Neuropsychological Rehabilitation

Theory, Models, Therapy and Outcome

Barbara A. Wilson
Fergus Gracey
Jonathan J. Evans
Andrew Bateman

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Foreword

Neuropsychological rehabilitation has shown tremendous growth in the last few decades, largely based on clinical acumen and experience. More recently, there has been much ado about the need for evidence-based rehabilitation based on the best available scientific evidence to support the effectiveness of interventions. The emphasis on evidence-based rehabilitation is often interpreted as standing in opposition to clinical judgment, when in fact these are complementary aspects of care, with sound clinical judgment required to apply the appropriate principles and techniques of treatment to the individual with a neurological disability. In addition, evidence-based treatment must incorporate the client's values, preferences and goals in the decision-making process in order to make the treatment accommodations that may ultimately determine the effectiveness of treatment.

The current volume by Barbara Wilson, Fergus Gracey, Jonathan Evans, Andrew Bateman and their colleagues is unique in the integration of scientific evidence, clinical judgment and patient-centred goals as the basis for neuropsychological rehabilitation. In discussing the evidence for the effectiveness of neuropsychological rehabilitation, the authors – who are all experienced clinicians as well as prolific researchers – emphasize that rehabilitation is an interactive process that requires the involvement of therapists, the person with a disability, and family, even extending to the person's community as a basis of support and reinforcement. The principles and examples that are elaborated in this volume provide a framework for approaching the individual client through an appreciation of their unique combination of limitations and strengths, motivation, personality and resources. The effectiveness of rehabilitation is evaluated in terms of the ability of rehabilitation to assist the client in reaching his or her personal goals and the relevance of treatment to the person's everyday functioning and quality of life, and these principles guide the planning and implementation of neuropsychological treatment.

It is most impressive that all of these principles and practices have been developed within an integrative treatment model at the Oliver Zangwill Centre for Neuropsychological Rehabilitation. This represents a major accomplishment, for at least two reasons. First, the Centre provides a therapeutic milieu that serves as a critical component of treatment. The therapeutic milieu establishes a sense of cohesion among clients and reinforces the relationship among clients and therapists, factors that are common to all forms of effective treatment and have a significant role in rehabilitation even when individual treatment techniques are based on specific, empirically based interventions. Second, the treatment provided at the Oliver Zangwill Centre fosters the integration of theory and practice, reflected in the use of learning theory, principles of cognitive re-organization, and goal planning as a method of organizing and evaluating client-oriented clinical activity.

Ultimately, the goal of rehabilitation is to assist people to lead meaningful, fulfilling lives. This is a tremendous undertaking, and one that cannot be accomplished without a

true collaborative effort. This volume provides a window into the techniques, principles and values that make this effort possible, and how they translate into effective neuropsychological rehabilitation.

Keith Cicerone

Preface

Neuropsychological rehabilitation is concerned with enabling people with cognitive, emotional or behavioural deficits to achieve their maximum potential in the domains of psychological, social, leisure, vocational or everyday functioning. In this book we address current rehabilitation practice as followed by those who believe that a holistic approach to rehabilitation is most effective. We define the holistic approach to rehabilitation as one that recognizes the fact that cognition, emotion and behaviour are dynamically interlinked. Consequently all these functions need to be addressed in an integrated way in brain injury rehabilitation by an interdisciplinary team.

We firmly believe that rehabilitation needs a broad theoretical base incorporating frameworks, theories and models from many different areas. Being constrained by one theoretical model can lead to poor clinical practice. We discuss the major theoretical approaches to rehabilitation, and the main changes in rehabilitation over the past 20 years. The major purpose of the book, however, is to present practical approaches to helping people with brain injury achieve those goals most valued by them and their families.

There are four sections to the book:

First, we review the background and guiding principles of neuropsychological rehabilitation. This includes an outline of the holistic programme of the Oliver Zangwill Centre for Neuropsychological Rehabilitation in Ely, Cambridgeshire, United Kingdom. This programme, influenced by the work of Yehuda Ben-Yishay and George Prigatano from the United States of America and Anne-Lise Christensen from Denmark, combines group and individual therapy to address the cognitive, emotional and social problems faced by adults with acquired, non-progressive brain injury.

In Section 2, we discuss the various groups run at the Centre and present descriptions of the structure of these groups. These include a group that is primarily educational (the Understanding Brain Injury Group), groups dealing specifically with cognitive problems (the Attention and Goal Management Group, the Memory Group), social skills (the Communication Group), emotional consequences of brain injury (the Mood Management Group), working with families, and groups that require bringing together skills and strategies (Project Group, Newsletter Group, Vocational and Independent Living Groups, Psychological Support Group).

Section 3 comprises nine detailed individual cases to illustrate how the principles outlined in Section 1 are applied in practice. The first six cases have been selected to illustrate aspects of the intensive holistic programme. Three further cases describe work with individuals whose difficulties precluded them from attending the intensive programme.

The final section is concerned with measuring the various outcomes of the Centre including clinical efficacy, research output and education. We discuss the challenges of measuring efficacy of a comprehensive holistic rehabilitation programme. Here we have been particularly influenced by the work of Keith Cicerone, James Malec and colleagues.

As neuropsychological rehabilitation is not only multidisciplinary but also interdisciplinary, we hope that many health service professionals will benefit from this book. The main audience is likely to be clinical neuropsychologists, clinical psychologists, speech and language therapists, occupational therapists, psychiatrists, neurologists, physiotherapists, social workers and nurses. Others may also find the book of interest, particularly relatives of people with brain injury, people with brain injury themselves, general practitioners and teachers.

Barbara A. Wilson

Section 1
Chapter 1

Background and theory

Towards a comprehensive model of neuropsychological rehabilitation

Barbara A. Wilson and Fergus Gracey

Introduction

Over the past 25 years or so there have been a number of major changes in neuropsychological rehabilitation. First it is now much more of a partnership than it was in the 1970s and 80s. Then doctors, therapists and psychologists decided what patients should and could hope to achieve from rehabilitation programmes. Now we discuss with families and patients what they hope to get from rehabilitation and we try to accommodate to this at least in part. Second, rehabilitation has moved well beyond the drills and exercise approach. We no longer find it acceptable to sit people in front of a computer or workbook in the belief that such exercises will result in improved cognitive and, more importantly, social functioning. Third, rehabilitation staff now follow a goal setting approach when planning rehabilitation programmes. Clients, families and staff negotiate appropriate goals and determine how these are to be achieved. Fourth, there is increasing recognition that the cognitive, emotional, social and behavioural consequences of brain injury are interlinked and all should be addressed in the rehabilitation process. Fifth, technology is playing a larger part than ever before in helping people with cognitive deficits compensate for their problems. Sixth, it is now more widely accepted that no one model, theory or framework is sufficient to deal with the many and complex difficulties faced by people with neuropsychological impairments following an injury or insult to the brain. Instead we need to draw on a number of models, theories and frameworks in order to achieve the best outcomes for those people requiring neuropsychological rehabilitation. We can see rehabilitation as a process whereby people with brain injury work together with health service staff and others to ameliorate or alleviate deficits that result from an insult to the brain. The main purposes of rehabilitation are to enable people with disabilities achieve their optimum level of wellbeing, to reduce the impact of their problems on everyday life and to help them return to their own most appropriate environments.

Of the many theories, models and frameworks that impact on rehabilitation, five areas are, perhaps, of particular importance, namely those of cognitive functioning, of emotion, of social interaction, of behaviour and of learning. Representative examples from each of these areas are described below. Models of relevance to the organization of the multidisciplinary team's work are presented. Consideration must also be given to theories and models of assessment, recovery and compensation. Following consideration of models

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representing aspects of these domains, a tentative, comprehensive model of neuropsychological rehabilitation is provided in an attempt to integrate the above-mentioned models and theories into a unified whole.

Theories and models of cognitive functioning

A number of models of cognitive functioning have proved helpful in rehabilitation. Models and theories of language, for example, have influenced the rehabilitation of people with aphasia over the past 15 or so years. Indeed, this is probably the area where such models first made their mark in rehabilitation (e.g. Byng and Coltheart, 1986). In 1991 Coltheart stated that in order to treat a deficit it is necessary to fully understand its nature and to do this one has to have in mind a representation of how the function is normally achieved. Without such a representation one cannot determine what kinds of treatment would be appropriate. Coltheart and others believe that cognitive rehabilitation should be based on theoretical models from cognitive neuropsychology. While we believe that this is too restrictive for reasons mentioned above, we accept that models of cognitive functioning are necessary to help us identify and understand the specific cognitive strengths and weaknesses of our clients. In other words these models are necessary but not sufficient. This view was put forward by Caramazza (1989) when he said 'There is nothing specifically about our theory of the structure of the spelling system (or reading system, the naming system, the sentence comprehension system and so forth) which serves to constrain our choice of therapeutic strategy. Merely "knowing" the probable locus of a deficit … does not, on its own allow us to specify a therapeutic strategy. To do so requires not just a theory of the structure of the damaged system but also, and more important, a theory of the ways in which a damaged system may be modified as a consequence of particular forms of intervention' (p. 382).

These models do not tell us how to rehabilitate people as they do not identify everyday problems or inform us how to treat a particular problem. Instead they tell us what bit of the model is malfunctioning. Their strengths lie in the fact that they tell us what the cognitive constraints are on any programmes we wish to implement; they also enable us to conceptualize processes, make predictions about intact cognitive functions and explain impairments to patients, relatives and staff. Some models have been invaluable in the identification of deficits. Take, for example, the dual route model of reading (Coltheart, 1985). This model postulates that there are at least two ways one can read a written word, namely the lexical (or whole-word route) and the phonological route whereby one converts letters to sounds. Take the word 'mint'. This can be read by either route; we can sound out M-I-N-T which conforms to the normal phonemic rules of English and it is also a known word so it is in our lexicon, our word knowledge store. In contrast, the word 'fint', a nonsense word that does not exist in English, can only be read via the phonological route. It is not in our word store because we have not met it before. With the word 'pint', however, we have to use the word knowledge store to read it correctly. If we used the letter-to-sound rules or the phonological route we would read this incorrectly as rhyming with mint. When Coltheart was developing this model he predicted that it would be possible to find patients with a deficit in the phonological but not the lexical route and vice versa. At that point such patients had not been identified so Coltheart assembled a screening test and he asked his clinical psychology and speech therapy colleagues working with neurologically impaired people to administer the screening test. Once this happened, the patients Coltheart predicted we would find *were* found. Those unable to read nonsense words like 'fint' are now said to have a 'phonological dyslexia' and those unable to read irregular

words like 'pint' are said to have a surface dyslexia. Not only has this model enabled us to explain such phenomena, but it has also resulted in a profound change in the assessment of acquired disorders of reading, over the past 20 or so years. In the 1970s most neuropsychological assessments of patients' reading abilities (at least in the United Kingdom) comprised of word lists such as The Schonell Graded Word Reading List and perhaps The Neale Analysis of Reading Ability to look at reading comprehension. Now we assess a wide variety of reading skills such as regular versus irregular words; concrete versus imageable words; parts of speech; word length; age of acquisition and so forth. This vast change came about as a direct result of theories of reading and language. Because these models tend to identify impairments rather than everyday problems they do not tell us *how* to rehabilitate people; they tell us what bit of the model is malfunctioning and not how to treat a particular problem.

It is not only in language that models of cognitive functioning have played a part. Take the influential Working Memory Model of Baddeley and Hitch (1974), originally put forward as a temporary stopgap model until something superseded it, which is still a useful model to this day. This has allowed us to conceptualize memory disorders, to understand why someone can have a normal immediate memory but problems after a delay or distraction or can have a normal phonological loop and visuo-spatial sketchpad but poor executive skills. Indeed the 'Central Executive' component of the Working Memory Model and the conceptually similar view of the Supervisory Attentional System put forward by Norman and Shallice (1980) has been of considerable influence in the understanding and assessment of the Dysexecutive Syndrome (which used to be more popularly known as the 'Frontal Lobe Syndrome'). There will be more of this later when we discuss the rationale behind the Problem Solving Group (Chapter 6).

Models of attention, perception and face processing among others have all played a part in helping us to understand cognition and the breakdown of cognition in people with brain injury. We need this understanding of cognitive functioning in order to get a good grasp of what is impaired and what is intact in the clients referred for neuropsychological rehabilitation, but we stress once again that an understanding of cognitive functioning is only part of the whole picture. As research into the interactions between cognition and emotion continues in the field of mental health (Harvey *et al.* (2004) present a thorough systematic review), a new challenge for neuropsychology emerges. This is how we model and assess aspects of cognition that may be fluid and dynamic rather than static, that appear to adapt according to the social and emotional salience of a situation, when trying to understand and do therapy or rehabilitation with clients with neurological problems.

Theories and models of emotional functioning

The management and remediation of the emotional consequences of brain injury has become increasingly important over the last 15 years. Prigatano (1999) suggests that rehabilitation is likely to fail if we do not deal with the emotional issues. Consequently, an understanding of theories and models of emotion is crucial to successful rehabilitation. Social isolation, anxiety and depression are common in survivors of brain injury (Fleminger *et al.* 2003; Wilson, 2004). McKinlay *et al.* (1981) thought that about two thirds of people surviving traumatic brain injury (TBI) would experience anxiety and depression. Seel *et al.* (2003) found that, in a sample of 666 out-patients with traumatic brain injury evaluated 10 to 126 months after injury, 27% met diagnostic criteria for major depressive disorder. Evans and Wilson (1992) found that anxiety was common in people

attending a memory group. Kopelman and Crawford (1996) found that 40% of 200 consecutive referrals to a memory clinic were suffering from clinical depression. Bowen *et al.* (1998) found that 38% of survivors of TBI experienced mood disorders. Williams *et al.* (2003) found that the prevalence of post-traumatic stress disorder (PTSD) following TBI ranges from 3% to 27%. In their own study they found 18% of 66 community living survivors of TBI experienced symptoms associated with PTSD. Deb *et al.* (1999) carried out diagnostic interviews using the International Classification of Diseases (ICD-10) with 164 TBI patients 1 year post-injury, finding 21.7% had a diagnosable psychiatric illness.

Gainotti (1993) distinguishes three main factors causing emotional and psychosocial problems after brain injury. First there are those resulting from neurological factors; second are those due to psychological factors and third are those due to psychosocial factors.

Neurological factors

An example of the first type of cause might be someone with brainstem damage leading to the so-called 'catastrophic reaction' (or pathological laughter and crying) in which swings from tears to laughter may follow in rapid succession. Anosognosia, or lack of awareness of one's deficits, is also frequently due to organic impairment. An important book on the topic of unawareness was published in 1991 (Prigatano and Schacter); it includes several rationales for the existence of anosognosia. Gainotti (1993) also addresses unawareness in some detail. Damage or disruption to fronto-temporo-limbic pathways is also associated with changes in the regulation and experience of affect (e.g. Starkstein and Robinson, 1991; Eames and Wood, 2003). Other models and theories that need to be taken into account are those of premorbid personality and neurological, physical and biochemical models such as those described by Robinson and Starkstein (1989). This addresses the issue of why emotional problems arise following an insult to the brain, but does not offer much help in understanding the psychological and psychosocial causes of emotional and mood disorders. With an increasing base of research related to cognitive processes, emotion and underlying neuroscience, the field of cognitive behavioural psychotherapy offers some helpful ideas.

Psychological factors

The second cause in Gainotti's three part classification (Gainotti, 1993) is where emotional problems are due to psychological or psychodynamic causes, including personal attitudes towards the disability. Goldstein (1959) was among the first to describe the emotional reaction to brain injury, noting how a 'catastrophic reaction' may arise whereby the individual withdraws or avoids situations or activities. This results in both maintenance of fears (as these remain unchallenged) as well as increasing disability through disuse of intact functions. Ben-Yishay (2000) describes this as a 'behavioural manifestation of threat to the person's very existence'. An example would be someone with an acquired dyslexia and consequent loss of self-esteem together with depression because of an inability to read, who avoids reading and mixing with peers, resulting in maintenance of depression and potential loss of other skills. Denial is also thought to be a relevant psychological process influencing the emotional outcome after injury. At some level patients are aware of their disabilities, but are unable to accept them. Caplan (1987) provides a readable account of denial. As denial can occur in conditions without any damage to the brain, there must (at least in some cases) be non-organic reasons for its cause (Gainotti, 1993). Post-traumatic stress disorder (which we discuss below) would also fit into this section. Fear of what might happen in the future, panic because one cannot

remember what has happened in the last few minutes, grief at loss of functioning and reduced self-esteem because of changes in physical appearance may all contribute to emotional changes. There has been a significant amount of research into forms or categories of coping and the relationship of these to outcome, some of which is summarized in Godfrey *et al.* (1996) stress-appraisal-coping model. These approaches converge on the therapeutically oriented cognitive-behavioural model, in that relationships between cognitive content (thoughts, beliefs, appraisals, assumptions, etc.), emotion and behaviour are hypothesized.

Ever since Beck's highly influential book *Cognitive Therapy and the Emotional Disorders* appeared in 1976, cognitive behaviour therapy (CBT) has become one of the most important and best validated psychotherapeutic procedures (Salkovskis, 1996). An update of Beck's model appeared in 1996 (Beck, 1996). One of its major strengths has been the development of clinically relevant and applicable research findings and models, and the challenging of some of the initial tenets of CBT by a broad research effort. This has resulted in a range of models applicable to mental health problems (depression, anxiety disorders, schizophrenia) and adjustment to health problems (e.g. pain, cancer). Pointing to the development of bridges between the cognitive and emotional, developments in the field of cognitive behavioural therapy now suggest that emotional processes such as worry and rumination are associated with disruption of memory, attentional and executive systems (Harvey *et al.*, 2004). It is these processes that are thought to be at least as important in vulnerability to disorders as the negative 'core beliefs' as originally described by Beck (e.g. Beck *et al.*, 1976). There is some evidence that integration of attention training skills into CBT following brain injury enhances efficacy (Mateer *et al.*, 2005; Tiersky *et al.*, 2005). The grounding of psychotherapy research in basic and cognitive neuroscience has also led to new ideas about ways of changing feelings and expression of anger (e.g. Paul Gilbert's (2000) use of compassionate mind training). Such developments in the mainstream of cognition-emotion and CBT research are ripe for application with survivors of brain injury.

Williams *et al.* (2003) discuss the use of CBT with two survivors of TBI. One was a young man whose girlfriend was killed in a car crash when he was driving. The other was a young woman who had been severely assaulted whilst travelling on a train. We describe her case and treatment later in this book (Caroline, Chapter 15). Williams *et al.* discuss the possible mechanisms for PTSD after TBI. These conditions were once thought to be mutually exclusive because the survivor would lack a memory for the event from which to develop vivid intrusive cognitions and avoidance behaviours (Sbordone and Leiter, 1995). However, given that PTSD seems to occur even when there is a loss of consciousness for the event, there could be two main mediating mechanisms to suggest how trauma-related material may be processed to lead to PTSD symptoms. First, survivors may recall 'islands of memory' for their trauma such as being trapped in the crashed car, or other secondary experiences, that could fuel intrusive ruminations (McMillan, 1996). Second, the survivors may be reminded of elements of their trauma event when exposed to similar situations, which serve to produce intrusive thoughts and fuel avoidance behaviours (Brewin *et al.*, 1996). Developments in the field of social neurosciences and the cognitive neuroscience of emotion allow us to think about the brain systems involved in this type of process. For example, the model of fear processing proposed by Joseph LeDoux (1996) allows us to understand how, at the neurological level, PTSD with loss of consciousness for the event may occur (see Brewin, 2001). McNeil and Greenwood (1996) described a survivor of TBI who was hyperaroused in, and avoidant of, situations that were similar to the trauma event, a road traffic accident, even though he had no declarative memory of the event. They

suggested that, if an event is unexpected, but has biological significance and, hence, emotional salience, it may lead to the event being stored (or 'burned in' to memory) despite disruption to areas of the brain that store declarative memories (see Markowitsch, 1998). Such a view would be compatible with the view that PTSD is due to a conditioning of fear. The mechanism responsible is that traumatic experiences can be processed independently of higher cortical functions (see Bryant, 2001). The model proposed by Joseph LeDoux suggests that frontal areas influence the inhibition of a previously conditioned fear response. King (2000) describes a case of PTSD following brain injury where executive impairment was present. The standard approach of exposure and restructuring work (from a CBT model) was applied, but the detailed recounting of the trauma resulted in what the authors call 'perseveration of emotional responding'. This discussion about the alteration of a well-understood psychiatric disorder when it occurs in the context of organic brain injury highlights the need to be cautious in our application of models of emotional disorder, such as those derived from CBT, when working with those with brain injury. Further research efforts are required to help build therapeutic models that integrate such issues.

As the traditionally intrapersonal fields of CBT and neurosciences grapple with integrating the basic science of brain systems involved in cognition and emotion, it is becoming clearer that processing of social context is central to the way in which emotions, behaviour and higher cognition is regulated. These ideas are supported through recent studies highlighting the impact of social context on awareness (Schönberger *et al*., 2006; Yeates *et al*., 2007), identity (Cloute *et al*., 2008) and wellbeing (Haslam *et al*. 2008). Thus the UK legislative guidance to involve family members (*National Service Framework for Long Term Conditions*, Department of Health, 2005) is now followed by theoretical support highlighting models of cognition and adjustment that are intimately tied to social context.

Thus, whilst one aspect not explicitly covered by Gainotti (1993) is the influence of pre-injury personality, culture, beliefs, values, goals, lifestyle and experiences, to some extent these ideas are represented in the growing body of work covered here. Further discussion is provided by Moore and Stambrook (1995), Tate (2003), Williams (2003) and Yeates *et al*. (2007).

Social factors

The third category put forward by Gainotti (1993) includes problems that arise for psychosocial reasons. An example of this might be someone who loses all his/her friends and colleagues following a brain injury and is thus very socially isolated. The social judgments of others and the impact of these on sense of self (Nochi, 1998), in addition to the important role of social group membership (Haslam *et al*., in press), have also been highlighted, recognizing the need to include social models in our thinking about the consequences of brain injury and rehabilitation.

The field of psychoanalysis, not typically considered an obvious choice for understanding the consequences of brain injury, is receiving renewed attention in the light of social and emotional neurosciences research. The approach brings a stronger emphasis on understanding the social and interpersonal in conjunction with the intrapsychic than is usually assigned to cognitive-behavioural models. One well-known proponent of this for the treatment of people surviving TBI is Prigatano. He describes his approach, based on the milieu-oriented approach of Ben-Yishay, and integrating ideas from Jungian psychotherapy, in his book *Principles of Neuropsychological Rehabilitation* (Prigatano, 1999). The

growing Neuro-Psychoanalysis movement seeks to develop explicit research, theory and clinical links between psychoanalytic theory and the neurosciences. Kaplan-Solms and Solms' (2002) book *Clinical Studies in Neuropsychoanalysis* marks out the territory in this developing field. The ideas of Antonio Damasio (e.g. 1998), and Frith and Wolpert (2003), also allow some integration of biological, psychological and social factors.

It seems our tripartite system of biological, psychological and social domains is becoming increasingly difficult to partition, and equally ideas about the separation of cognition and emotion are equally difficult to maintain. In this respect the ideas of Vygotsky (1960/1978) regarding the development of higher psychological processes as mediated by the biological and social can perhaps be viewed in an encouraging new light.

Theories and models of behaviour

Models and theories from behavioural psychology have been employed in neuropsychological rehabilitation for more than 40 years. They have provided some of the most useful and influential theoretical contributions to rehabilitation, not only for the understanding, management and remediation of disruptive behaviours but also for the remediation of cognitive deficits (Wilson, 1987, 1991, 1999; Wilson *et al.*, 2003). Behavioural theories are valuable in neuropsychological rehabilitation because they benefit assessment, treatment and the measurement of rehabilitation efficacy.

The principles involved in theories of behaviour come from research in social and experimental psychology (Franks and Wilson, 1975). This includes learning theory, which we cover in the following section. The principles involve environmental change and social interaction rather than the use of biological procedures to bring about change (Frank and Wilson, 1975).

Kazdin and Hersen (1980) suggested that followers of the behavioural approach have four main characteristics:

i) A strong commitment to the empirical evaluation of treatment and intervention techniques
ii) A general belief that therapeutic experiences must provide opportunities to learn adaptive or prosocial behaviour
iii) Specification of treatment in operational and, hence, replicable terms
iv) Evaluation of treatment effects through multiple-response modalities with particular emphasis on overt behaviour (p. 287).

The underlying theoretical frameworks of behavioural approaches come from a number of fields including learning theory, neuroplasticity, information processing, linguistics, psychiatry, and so forth. This richness and complexity of theoretical support and clinical treatment means that behavioural medicine can be applied to a wide range of patients, problems and situations. Although there is a wide variety of behavioural assessment and treatment techniques, they tend to share common themes. First, all are concerned with the development of reliable and valid assessment instruments. Pearce and Wardle (1989) believe these instruments are the hallmark of the behavioural scientist. Second, liaison with other disciplines is another characteristic of behavioural medicine. From its beginnings in learning disability to its wide application in many medical conditions, such as diabetes, chronic pain, obesity, addiction and brain injury, behavioural scientists frequently work in multidisciplinary and interdisciplinary teams making such liaison

crucially important to success. Third, all behavioural methods involve careful monitoring and evaluation of treatment efficacy. This is often done at the individual level and the widespread use of single case experimental designs grew directly out of behavioural psychology (Wilson, 1987).

Wilson *et al.* (2003), in a book about behavioural approaches to neuropsychological rehabilitation, suggest the following reasons for the success of behavioural methods for the treatment of people with brain injury, namely:

1. There are many treatment techniques to either decrease problem behaviours or increase desirable behaviours that can be adapted or modified for use with our patient population.
2. The targets, aims and goals of therapy are made clear from the beginning of each programme. Unlike, say, interpretative psychotherapy that arrives at its specification at the *end* of therapy, behavioural approaches specify the goals at the beginning of the process. Furthermore, the goals are explicit, small and usually easy to achieve.
3. Assessment and treatment are frequently inseparable in behavioural treatment programmes, unlike other treatments. Neuropsychological or cognitive assessments, for example, are typically unrelated or indirectly related to the treatment. Poor scores on intelligence tests or memory tests are not targeted for treatment; we do not teach people to pass these tests. The scores are important in helping us to understand a person's cognitive strengths and weaknesses and help us plan our interventions appropriately but they do not inform us in any detail about everyday problems, how families cope, what brain injured people want to achieve or how environments may affect behaviour. For such information we must employ behavioural assessments that are often part of the treatment strategy itself.
4. Behavioural interventions are continuously monitored. Without measurement we are in danger of giving subjective or intuitive opinions about behavioural change or treatment effectiveness. Some of the most valuable evaluation techniques in neuropsychological rehabilitation are the single case experimental designs developed in the field of behavioural medicine. These designs help us tease out whether change is due to natural recovery (or some other non-specific factor) or to our intervention.
5. Within a behavioural approach it is possible to individualize treatment and this is particularly helpful for some brain injured patients who will probably not respond to 'packaged treatment' such as computerized cognitive retraining or memory exercises. These 'packaged' programmes have not been designed to take into account the complex mixture of cognitive, social, emotional and behavioural programmes of brain injured people and may have not been properly evaluated. In contrast, behavioural programmes typically take into account the biological condition of the individual, precipitating events, consequences of events, social factors and the environment in which the individual is functioning. 'Lesions in the same general areas do not always show the same symptoms and potential for restitution' (Finger and Stein, 1982), thus a more individually oriented approach to therapy is called for, 'one that would take into account not only features of the lesion, but factors such as motivation, age, experiential history, and the status of the rest of the brain' (Finger and Stein, 1982).
6. Behavioural approaches provide a set of principles and a structure to follow when designing treatment programmes. Task analysis, goal setting, appropriate and detailed assessments, recording, monitoring and evaluating the programme provide sound guidelines for psychologists, therapists or teachers to follow.

7. Numerous studies testify to the success of behavioural approaches in neuropsychological rehabilitation (e.g. Taylor and Persons, 1970; Lincoln *et al.*, 1982; Alderman, 1996, Wilson, 1999).

Models and theories of learning

Learning theory is one of the cornerstones of behaviour therapy and behaviour modification, the other main theoretical influences coming from biological, cognitive and social psychology (Martin, 1991). There is little doubt, though, that the original behavioural treatments grew out of learning theory. Eysenck (1964) for example defined behaviour therapy as 'the attempt to alter human behaviour and emotion in a beneficial manner according to the laws of modern learning theory' (p. 1). Wolpe (1969) said it was 'the use of experimentally established principles of learning for the purpose of changing unadaptive behaviour' (p. vii). Martin (1991) says 'the inspiration for the development of numerous therapeutic techniques has come from theories and findings in the learning literature' (p. 2). A widely accepted definition of learning is that by Kimble (1967) who said that learning is a relatively permanent change in behaviour that occurs as a result of reinforced practice. The most important learning theories leading to early behaviour modification techniques were those of classical and (even more importantly) operant conditioning. Watson (1913) and Skinner (1938 and 1953) are, perhaps, the names most associated with operant conditioning, but people such as Rescorla (1966), Lovaas (1967) and Kazdin (1978) were some of the most important names in bringing operant conditioning principles into clinical practice through their work with people having severe developmental learning difficulties. Most psychologists in rehabilitation today who have been influenced by principles from operant learning theory do not adhere to the rigid behaviourism of the past. Instead they modify these procedures or just use some of the component elements such as task analysis, shaping procedures and behavioural assessments to make them appropriate for clients with brain injury. Furthermore, learning theories are often combined with other theoretically driven approaches in an attempt to provide the best clinical practice for people with brain injury.

One theory of learning that has been very influential in rehabilitation is errorless learning first described by Terrace (1963). Errorless learning is a teaching technique whereby people are prevented, as far as possible, from making mistakes while learning a new skill or acquiring new information. Instead of learning by trial and error, the correct responses are presented or demonstrated until the behaviour is established. This is followed by a gradual fading out of the support or prompts. In other words, this is an approach whereby the task is manipulated to eliminate or reduce errors. Typically, tasks are gradually made more difficult (even though this may increase errors) both to approximate real life and to maintain attention during therapy. Terrace's work was with pigeons but errorless learning principles were soon adapted for use with people with developmental learning disabilities (Sidman and Stoddard, 1967; Cullen, 1976; Walsh and Lamberts 1979). Still widely used for the teaching of self care and cognitive skills in learning disability, it has only recently been widely used in cognitive rehabilitation (although Wilson (1981) describes its use in this field since the late 1970s). The reason errorless learning is now accepted in cognitive rehabilitation came about because of a second theoretical impetus, namely research into implicit learning (i.e. learning in the absence of conscious recollection). We have known for many years that people with severe memory deficits can learn certain skills or information normally or nearly normally despite having no conscious memory of having

seen the task or information before. This is known as implicit memory in contrast to explicit memory where there is conscious recollection that one has been exposed to the information earlier. In 1994, Baddeley and Wilson demonstrated the superiority of errorless over errorful learning for people with severe memory disorders following non-progressive brain injury. The first study was a theoretical study suggesting that errorless learning was beneficial for memory-impaired people because it capitalized on their intact (or relatively intact) implicit learning system. It was suggested that in order to benefit from our mistakes, we need to remember our mistakes and to do this one needs an episodic memory. In the absence of this system one has to depend on implicit memory, which is not good at error elimination. In these circumstances it is better to avoid errors so they do not become strengthened or reinforced. Page *et al.* (2006) confirm the importance of implicit memory in errorless learning.

Wilson *et al.* (1994) also demonstrated the effectiveness of errorless learning for teaching real-life tasks to a variety of people with severe memory problems. The group included people with different diagnoses (e.g. TBI, stroke, encephalitis), of different ages and of different times post-insult. A series of studies by Linda Clare and her colleagues showed that errorless learning is also a useful method for teaching practical, everyday information to people with dementia of the Alzheimer type (Clare *et al.*, 1999, 2000, 2001). In some instances, information taught is well retained at 1–3 years follow-up despite the fact that the disease is progressing. Potentially this is an important clinical finding suggesting that some practical information can be taught in the early/moderate stages of Alzheimer's disease that can be retained (possibly with practice) when the disease progresses and could enable people with dementia to remain for longer outside institutional care.

At present the conclusions to several research studies into errorless learning are that, first, it is superior to trial-and-error learning for people with memory deficits; second, active participation is required; third, other principles from learning theory and memory rehabilitation should be incorporated into treatment; fourth, it is not clear whether errorless learning is the method of choice for people with cognitive problems other than memory (e.g. language) nor whether it is the better/best method for other problems (e.g. motor difficulties).

In addition to the behavioural principles and cognitive models of learning highlighted above, there is a need to ensure learning is generalized beyond the treatment setting or clinical session and maintained over time. Whilst for many, generalization training involving stepped strategy use and skills training in relevant contexts, environmental supports and changes is the only option, some may be able to undergo a deeper process of personal change and adjustment. Developments in the field of cognitive behavioural therapy (Bennett-Levy *et al.*, 2004) and the underlying research base (e.g Teasdale and Barnard 1993; Conway and Pleydell-Pearce, 2000) point to the importance of experiential learning in catalysing changes in the cognitive representations that guide our sense-making and personally salient goal directed activity, especially of those in emotional distress. Carver and Scheier's (1990) 'goal process' account of emotion suggests that discrepancy between a personally salient goal and current status in relation to that goal determines our emotion. So making good progress to such a goal is thought to underpin good mood, whilst encountering barriers to reaching a goal may engender frustration or anger. Thus there is both theoretical and research grounds to focus on the relationship between activity, personally meaningful goals, expectations or beliefs, and identity in the practice of rehabilitation. Joanna McGrath (e.g. McGrath and King, 2004) and Mark Ylvisaker (e.g. Ylvisaker

and Feeney, 2000) have extended these principles into approaches to therapy and rehabilitation. The importance of learning being linked to both social context, i.e. placed in or explicitly linked with the client's meaningful activity, as well as underlying beliefs, values and representations of self or identity, are made by both. These principles are outlined in more detail in Chapter 4 and in some of the cases presented in this book, for example describing our work with Judith (Chapter 17) and Yusuf (Chapter 16).

Other useful models and theories: assessment, recovery and compensation

Assessment

Assessment can be defined as the systematic collection, organization and interpretation of information about a person and his/her situation. It is also concerned with the prediction of behaviour in future situations (Sundberg and Tyler, 1962). There are a number of models and approaches to neuropsychological assessments including those derived from models of cognitive functioning mentioned above. Other models of assessment include (1) the psychometric approach based on statistical analysis, (2) the localization approach whereby the examiner attempts to assess which parts of the brain are damaged and which are intact and (3) the ecologically valid approach in which attempts are made to predict real-life problems. Although these approaches enable us to build up a picture of a person's cognitive strengths and weaknesses, they are unable to pinpoint in sufficient detail the nature of the everyday problems and what problems need to be addressed, to tell us how the family is coping or to determine whether the problems are exacerbated by depression, anxiety or fatigue. Behavioural and functional assessments are required to complement the information obtained from the standardized tests. Wilson (2002) discusses these approaches in greater detail.

Recovery

If further recovery is expected in the person with brain injury we need to know this before implementing rehabilitation so that we can try to determine whether the treatment or recovery is responsible for any change in behaviour (Wilson *et al.*, 2000). Although natural recovery can sometimes be ruled out by ensuring there is a stable baseline prior to treatment, theories of recovery are helpful in understanding what may be happening to the people we are working with. Recovery in the first few minutes after an insult to the brain probably reflects the resolution of temporary dysfunction without accompanying structural damage. Recovery after several days is likely to be due to the resolution of temporary structural abnormalities such as vascular disruption or oedema, or to the depression of metabolic enzyme activity. Recovery after several years might be achieved through regeneration, diaschisis and plasticity. For a more detailed discussion of recovery see Whyte (1990), Wilson (1998) and Robertson and Murre (1999). As it becomes possible to study neurotransmitter changes both acutely and over time, the possible protective or toxic effects of certain neurochemicals are being identified. For example, in some exciting research, Don Stein and his team (e.g. Stein, 2001) have identified the potential neuroprotective effect of oestrogen in the acute recovery stage post-injury. The suggestion is made that use of neuroprotective treatment in the acute stage can provide a better 'matrix' for the provision

of effective rehabilitation in the post-acute phase. Research into factors influencing neuroplasticity and early recovery following injury is in the early stages but may yield important results for rehabilitation in the acute and post-acute phase.

Compensation

Compensation is one of the major tools for enabling people with brain injury to cope in everyday life. Wilson and Watson (1996) described a framework for understanding compensatory behaviour in people with organic memory impairment. The framework was developed by Bäckman and Dixon (1992) and further modified by Bäckman and Dixon (1999); it distinguishes four stages in the evolution of compensatory behaviour, namely origins, mechanisms, forms and consequences. Wilson (2000) went on to use this framework to consider compensation for a variety of cognitive deficits. Evans *et al.* (2003) investigated factors that predict good use of compensations for memory impairment. The main predictors appear to be age (younger people compensate better), severity of impairment (very severely impaired people compensate less well), specificity of deficit (those with widespread cognitive deficits appear to compensate less well than those with more specific deficits) and pre-injury use of strategies (those using some compensatory aids pre-injury appear to compensate better).

This is an area where further work is required. If we can predict who is likely to compensate without too much difficulty, we can target our rehabilitation to help those who are less likely to compensate spontaneously.

Organizational models

As our understanding of the complex needs arising following brain injury increases, it becomes clearer that multi-professional input is often required at least at some stage of the recovery and rehabilitation process. It would be naïve, as well as contrary to established organizational research, to think that a group of professionals with the same or at least overlapping goals, despite different skills and professional backgrounds, can organize their rehabilitation effort effectively with little effort. A recent study of multidisciplinary teams suggests that multidisciplinarity does not guarantee better outcome (Fay *et al.*, 2006). Their findings suggest that the quality of team process is a key factor in allowing the potential benefits of the broader range of skills in multidisciplinary teams to be realized. Group process and team-functioning models converge on the importance of factors variously described in terms of shared mental models, vision, understanding, values, mentality, or 'superordinate' goal. Reflexivity and safety are also considered to be important factors. This field thus leads to consideration of the ways in which the rehabilitation endeavour is structured and organized, the nature, frequency, attendance and structure of meetings, the documentation used to maintain shared understanding, amongst other things.

Reflecting then on the range of models that can be drawn upon, and emerging research findings across biopsychosocial domains, it seems necessary to think about models that integrate organically based neurological and neuropsychological changes with models of cognition, affect, social interaction and identity. One can argue that a comprehensive approach to rehabilitation, which is firmly grounded in the context of personally and socially meaningful interactions and activity, requires a wide range of models, as well as a system for organizing and integrating the team, client and family's application of the models.

Towards a comprehensive model of neuropsychological rehabilitation

We conclude this chapter with an attempt to synthesize these theories and models plus some others into a more comprehensive model of rehabilitation, as portrayed in Figure 1.1.

Starting with the person with the cognitive impairments and his/her family, the premorbid personality and lifestyle of the brain injured person (and other family members) is likely to impact on the needs and desires of these people and thus on the rehabilitation offered. Consequently, it is desirable to carry out an assessment of premorbid lifestyle and behaviour either through interview or through the administration of one of the measures comparing pre- and post-morbid characteristics. The BICRO (Brain Injury Community Rehabilitation Outcomes; Powell *et al.*, 1998) attempt to identify pre- and post-morbid characteristics and the EBIQ (European Brain Injury Questionnaire; Teasdale *et al.*, 1997) is a checklist referring to symptoms experienced in the last month. Clinical interview focusing on pre-injury beliefs, values and goals, at individual, family and cultural levels, is also warranted.

The nature, extent and severity of the brain damage will need to be determined. This information may be obtained from hospital notes and/or the referral forms, neurological investigations and imaging studies. Neuropsychological investigations may also add to the picture. It is helpful if people are monitored over time, particularly if a deteriorating condition is suspected. It should be recognized that repeated neuropsychological assessments may not provide reliable information as improvement in scores may simply reflect a practice effect whereas no change in scores may mask a deterioration, again because of a practice effect (Wilson *et al.*, 2000).

Further recovery may need to be considered especially if the person with brain injury is seen in the early days, weeks or months after an insult. Theories of recovery are relevant here. The cause of the brain damage is also relevant. People with TBI, for example, may show recovery for a longer time than, say, someone with encephalitis (Wilson, 1998).

One of the most important tasks in rehabilitation is the identification of current problems. There are several theoretical frameworks one can draw on when assessing these problems. Information from standardized tests that help us build up a profile of strengths and weaknesses needs to be complemented by the information from functional or behavioural assessments and clinical interviews to build up a picture of how the problems affect everyday life.

Cognitive, emotional, psychosocial and behavioural problems should be evaluated more thoroughly through reference to a more detailed model. Models of language, reading, memory, executive functioning, attention and perception can provide details about cognitive strengths and deficits. Models derived from cognitive-behavioural research and psychotherapy can contribute to understanding of emotional and psychosocial problems, while a behavioural model such as a functional analysis to identify the antecedents, specify the actual behaviour and determine the consequences of any given behaviour allows better conceptualization of disruptive or inappropriate behaviours. Since the injury impacts on the family and social networks of the person with the brain injury, attachment and systemic models are also useful in understanding altered relationships and patterns of communication, and how these may be inadvertently presenting barriers to adjustment, behaviour change or uptake of services.

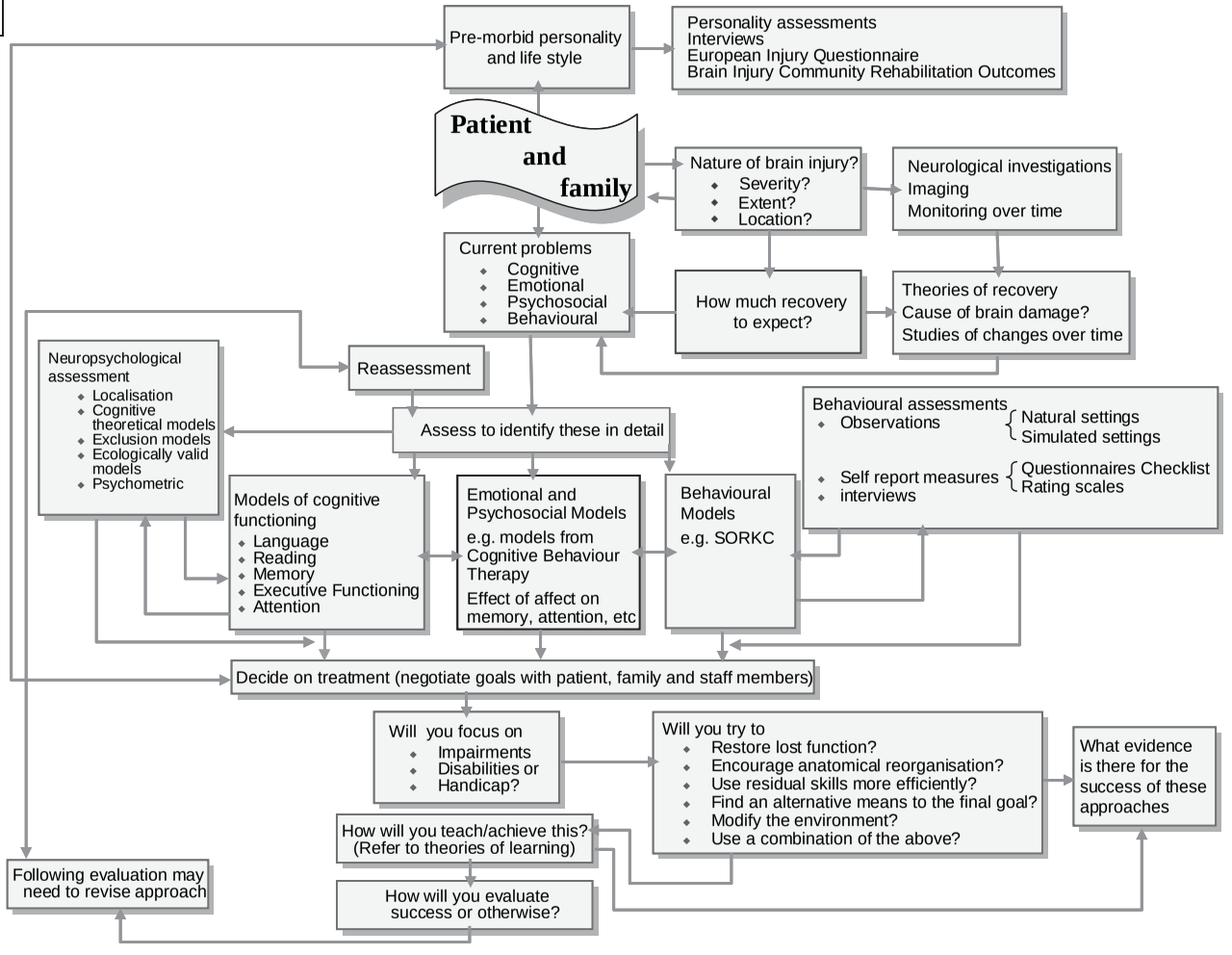

Figure 1.1 'Towards a comprehensive model of cognitive rehabilitation' reproduced with permission from Psychology Press (Taylor and Francis) Hove. SORKC = Stimulus, Organism, Response, Contingency and Consequences.

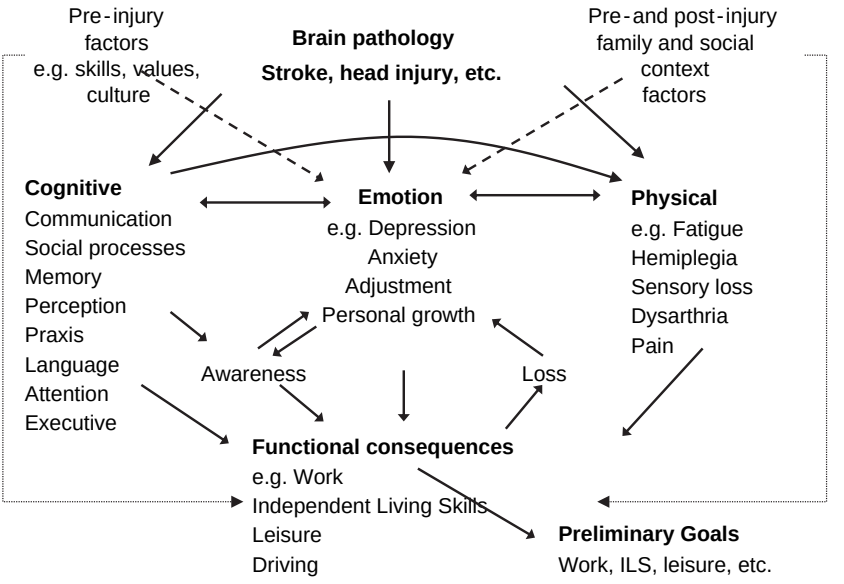

Figure 1.2 A biopsychosocial model of the consequences of brain injury based on that described by Jon Evans (2006). This format is used at the Oliver Zangwill Centre to map the assessment results across the team, to develop a shared formulation or understanding with client, family and professionals. ILS = independent living skills.

Once the problems are identified, and models used to develop a formulation or set of hypotheses highlighting patterns of interaction and influence between factors, one can decide on the rehabilitation strategies. In clinical practice where there are different professionals working with a patient, the organization and sharing of such information is a challenge. One means of meeting this challenge is through the systematic sharing and organization of assessment materials, gathered according to the models that guide the practice of the different professionals involved. For example by bringing the team together to draw out pre-injury individual vocational and family information (the context for thinking about the person and the injury), details of the nature of injury, and the cognitive, emotional, physical and communication consequences, an understandable account of the presenting problems and social participation restrictions can be developed. This is drawn out in Figure 1.2.

As will be seen later in this book, this process provides a valuable starting point for the team, client and family to develop and share an understanding of the challenges they face post-injury and in rehabilitation.

The next step involves the negotiation of suitable goals. Given that one of the main goals of rehabilitation is to enable people to return to their own most appropriate environment, the person with brain injury, family members and rehabilitation staff should all be involved in the negotiating process. The main goals may attempt to improve impairments, activity restrictions or social participation. Although there may be times or stages in the recovery process where it is appropriate to focus on impairments, the majority of goals for those engaged in cognitive rehabilitation will address activity and social participation. There is obviously more than one way to try to achieve any goal. Rehabilitation efforts may aim to restore lost functioning, or facilitate anatomical reorganization. Rehabilitation may also help people use their residual skills more efficiently, find an alternative means to the final

goal (functional adaptation), use environmental modifications to bypass problems or use a combination of these methods. Within the World Health Organization model (see Wade (2005) for a useful presentation and extension of the model), rehabilitation efforts could be considered as addressing domains or levels of functioning (i.e. impairments, activity or social participation restrictions), or addressing personal and social contexts (including for example the client's beliefs, appraisals and emotions, as well as those of significant others). Our shared formulation may often help the team, client and family think about where changes might be made. Whichever method is selected, one should be aware of theories of learning. In Baddeley's words, 'A theory of rehabilitation without a model of learning is a vehicle without an engine' (Baddeley, 1993, p. 235). In light of recent work on behaviour change, emotional adjustment and identity, one might extend this notion of learning to include post-injury reconstruction of identity, as in the work of Mark Ylvisaker (e.g. Ylvisaker and Feeney, 2000).

Evidence for the success of these approaches also needs to be taken into account. The final question is how best to evaluate success or otherwise. Consider Whyte's (1997) view that outcome should be congruent with the level of intervention. If intervening at the disability or activity level then outcome measures should be measures of disability and so forth. As most rehabilitation is concerned with the reduction of activity and social participation restrictions, outcome measures should reflect changes in these domains, for example, how well does someone who forgets to do things now remember to do things? There are studies that directly assess such changes (Wilson *et al.*, 2001) described in further detail in Chapter 2. It may also be relevant to assess the hypotheses suggested by formulation, as influencing the presenting problems. Inclusion of such measures is detailed in some of the clinical cases described later in the book (see for example Chapter 15 and 17). The final message of this chapter and indeed this book is that it is not only possible, but also necessary to combine theory, scientific methodology and clinical relevance.

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Chapter 2

Evidence for the effectiveness of neuropsychological rehabilitation

Barbara A. Wilson

Introduction

Although, as argued in Chapter 1, neuropsychological rehabilitation is partly concerned with the remediation or alleviation of emotional, behavioural and motor consequences of brain injury, it is probably true to say that the major role of neuropsychological rehabilitation is the treatment of cognitive deficits resulting from damage to the brain. What exactly is meant by the term 'cognitive rehabilitation'? It is certainly aimed at a number of different cognitive functions including memory, attention, problem solving, communication, perceptual and spatial deficits. It should encompass methods for restoring cognitive functions and methods to teach compensatory strategies. It should also be concerned with reducing problems faced in everyday life. As indicated in Chapter 1, we need to recognize that rehabilitation is an interactive process involving the disabled person, therapeutic staff and, where possible, relatives and members of the wider community. As a consequence of these views, we suggest that cognitive rehabilitation is a process whereby brain injured people work together with healthcare professionals to remediate or alleviate cognitive deficits arising from a neurological insult. We are particularly concerned here with people who have sustained a non-progressive insult to the brain such as traumatic brain injury (TBI), encephalitis, hypoxic brain damage or a stroke. This is not to deny the value of rehabilitation for people with progressive conditions such as Alzheimer's disease and we accept that some valuable work is being done in this area (Clare and Woods, 2001). Whether working with people with progressive or non-progressive conditions, rehabilitation should help brain injured people and their families to understand, come to terms with, bypass, or reduce cognitive deficits in order to function as adequately as possible in an environment that is most appropriate to them.

A brief history of the development of cognitive rehabilitation

The origins of rehabilitation go back a long way, as witnessed in the Edwin Smith surgical papyrus document acquired by Smith in 1862 (described by Walsh, 1987), showing that treatment of brain injured people can be traced back to Ancient Egypt some 2500 to 3000 years BC. The examples from the Smith papyrus, provided by Walsh, are, however, more related to medical aspects of treatment rather than rehabilitation as we understand it today. Modern-day rehabilitation probably began during the First World War as a result of

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improvements in the survival rates of head injured soldiers (Goldstein, 1942). A review of the history of neuropsychological rehabilitation in Germany suggests that many of the rehabilitation procedures developed in special military hospitals during the First World War are, to some extent, still in use today (Poser *et al.*, 1996). Indeed the first book written on rehabilitation of soldiers who survived gunshot wounds to the head (Poppelreuter, 1917) argued for an interdisciplinary approach between psychology, neurology and psychiatry. This book dealt with the treatment of visual impairment in a group of 700 soldiers seen in Germany between 1914 and 1916. In a paper published the following year, Poppelreuter (1918) stressed the importance of the patient's own insight into the effects of his disabilities.

Goldstein (1942), also writing about the First World War, argued for the importance of cognitive and personality deficits following brain injury. Along with his fellow countryman, Poppelreuter, Goldstein was one of the first people to use what are now called cognitive rehabilitation strategies even though he himself did not use that term (Prigatano, 1986). In 1918, Goldstein (quoted by Poser *et al.*, 1996) was concerned with decisions as to whether to try to restore lost functioning or to compensate for lost or impaired functions. This debate is continuing to the present day. The same can be said of Goldstein's interest in work therapy (vocational therapy), another important part of modern rehabilitation.

During the Second World War, Luria (1963) in the Soviet Union, and Zangwill (1947) in the United Kingdom, were both working with brain injured soldiers. In a paper describing Luria's contributions to neuropsychological rehabilitation, Christensen and Caetano (1996) suggested that the Second World War was the most significant factor in Luria's development of neuropsychological rehabilitation methods. Like Goldstein (1942), both Luria and Zangwill believed firmly in the principle of 'functional adaptation' whereby an intact skill is used to compensate for a damaged one. The ideas put forward by Luria (1963), Luria *et al.* (1969) and Zangwill (1947) are well worth reading today for the insights they offer. Among other things, Zangwill discusses the principles of re-education, and refers to three main approaches to rehabilitation, being 'compensation', 'substitution' and 'direct retraining'. In the USA the most influential people in rehabilitation during the Second World War were Cranich and Wepman who both worked with people with aphasia (Cranich, 1947; Wepman, 1951), and Aita who set up a day treatment programme for men with penetrating injuries to the brain (Aita, 1946, 1948).

The next major move forward appeared to result from the six-day war in Israel (Najenson *et al.*, 1974; Ben-Yishay, 1978). The latter describes in some detail the origins of Ben-Yishay's approach, the evolution of the therapeutic milieu concept and the philosophy behind his thinking. At about the same time as Ben-Yishay was developing his therapeutic milieu programme, greater numbers of survivors of road traffic accidents prompted the growth of specialist rehabilitation centres in the USA, such as the Rancho Los Amigos Hospital in California (Malkmus *et al.*, 1980). The first programme to call itself a 'cognitive rehabilitation programme' was probably that of Diller in New York (Diller, 1976). Diller and Ben-Yishay have worked closely together for over 20 years and the former was one of Ben-Yishay's main supporters in setting up the Israeli programme. Prigatano's programme in Oklahoma City was also greatly influenced by Ben-Yishay (Prigatano, 1986), adopting a holistic approach (described below). Prigatano later moved his programme to Phoenix, Arizona. Christensen opened a similar programme in Copenhagen, Denmark in 1985 (Christensen and Teasdale, 1995) and Wilson and colleagues opened the Oliver Zangwill Centre for Neuropsychological Rehabilitation in Cambridgeshire, England in 1996 (Wilson *et al.*, 2000).

Implementing neuropsychological and cognitive rehabilitation: differing views and influences

Gianutsos (1989) suggests that cognitive rehabilitation is born of a mixed parentage, including neuropsychology, occupational therapy, speech and language therapy and special education. Others hold different views. McMillan and Greenwood (1993), for example, believe that rehabilitation should draw on clinical neuropsychology, behavioural analysis, cognitive retraining and group and individual psychotherapy. Some believe that only one 'parent' is necessary: Coltheart (1984), for example, said that rehabilitation programmes should be based upon a theoretical analysis of the nature of the disorder to be treated. Mitchum and Berndt (1995) suggested cognitive rehabilitation should be concerned with the development of rational therapies based upon a theoretical analysis of the nature of the disorder that is to be targeted for treatment.

Most people working in cognitive rehabilitation seem to believe that theoretical models are necessary to design appropriate treatment while some believe these models are not necessarily sufficient on their own. There is sometimes disagreement as to what constitutes a theoretical model. Gianutsos (1991), for example, claims that cognitive rehabilitation is the application of theories of cognitive sciences to TBI rehabilitation. Apart from the fact that it is not only people with TBI who receive cognitive rehabilitation, Gianutsos' approach does not appear to be influenced by theories from cognitive science as she favours the repeated practice approach whereby patients carry out cognitive exercises on a computer (Gianutsos, 1981, 1991). There is little evidence in these papers of theories of cognitive neuroscience. Similarly, Robertson (1991) claims that some of the theories put forward are nothing more than collections of headings to guide assessment and treatment. He concedes that these approaches may make intuitive sense, but they are not theoretical models.

One approach we would like to consider here is the holistic approach as pioneered by Diller (1976), Ben-Yishay (1978) and Prigatano (1986). Proponents of this approach regard it as futile to separate the cognitive consequences of brain injury from the emotional, social and functional consequences. Given that how we feel emotionally affects how we think, remember, communicate and solve problems and also affects how we behave, we need to acknowledge that these functions are interconnected, often hard to separate and all need to be dealt with in rehabilitation. Most holistic programmes are concerned with increasing a client's awareness, alleviating cognitive deficits, developing compensatory skills, and providing vocational counselling. All such programmes provide a mixture of individual and group therapy. 'Although there is as yet no irrefutable evidence of the success of the holistic programmes, they appear to have been subjected to more research on efficacy than other approaches' (Diller, 1994). Furthermore, Cope (1994) believes that there is reasonably convincing evidence that comprehensive rehabilitation does make a substantial difference in the reduction of handicap for brain injured patients. Cognitive rehabilitation, then, is carried out in a number of ways. Combining the strengths of these different approaches is probably the right way forward.

Evidence that cognitive rehabilitation is clinically effective

Problems in research design

Just as we do not ask general questions about surgery or pharmacological procedures, such as 'Does surgery work?' or 'Do drugs work?' we should not pose the question

'Does rehabilitation work?' Any research question should be posed so that it is answerable. The questions should be more specific such as 'Which of these two methods leads to better recall?' or 'Do people who attend a psychological support group report fewer emotional problems than those who attend a recreational therapy group?' We need to find out which rehabilitation programmes, strategies or techniques work for which people under which circumstances.

Many health economists, managers, scientists, physicians and others believe there is only one way to evaluate the effectiveness of rehabilitation and that is through the use of randomized, controlled trials (RCTs), preferably under double-blind conditions. Yet, as Mai (1992) points out, it is hard to see how double-blind conditions can be applied in rehabilitation. Therapists and psychologists cannot be blind to the treatment they are giving and in most cases neither can patients be blind to the treatment they are receiving. It is possible in some cases, however, to conduct single-blind trials where an assessor does not know which treatment has been provided (see, for example, Wilson, 1997). The Proceedings of the Subcommittee on TBI Rehabilitation (National Institutes of Health, 1998) suggest that evaluation studies of rehabilitation should include only those where the researchers evaluating programmes are not the clinicians carrying out the programme.

Of course there is a place for RCTs (leaving aside the more controversial decision to make them double-blind), and certain investigations can only be carried out in this way. Nevertheless, we have to use a variety of research designs and not just RCTs in order to evaluate cognitive rehabilitation. Andrews (1991) said that the RCT '. . . is a tool to be used, not a god to be worshipped' (p. 5). He went on to say that the RCT is an excellent tool in research where 'the design is simple, where marked changes are expected, where the factors involved are relatively specific, and where the number of additional variables likely to affect the outcome is few and can be expected to be balanced out by the randomisation procedure' (p. 5). Unfortunately, most rehabilitation studies are more complex and randomization is often impossible. It would be hard, for example, to have a control group receiving no rehabilitation or different treatment in a rehabilitation centre committed to providing a holistic programme for all its clients.

Another important factor making RCTs very difficult, if not almost impossible, in rehabilitation research is that it is rarely, if ever, ethical to randomly allocate patients to treatment or no treatment. For example, in one study (Wilson *et al.*, 1994), we found that severely head injured people admitted to general wards without specialist head injury services were more likely to develop contractures, inhalation pneumonia, and behaviour problems than those admitted to specialist wards. Randomly allocating to treatment or no treatment in order to conduct a tighter piece of research in this area would be difficult if not impossible to justify.

Although still few in total, there is a gradual increase in the number of studies employing an RCT design to evaluate rehabilitation interventions. One of the earlier studies looked at a specific question, namely whether problem solving training (PST) benefited patients with brain injury more than non-specific training (von Cramon *et al.* 1991). Patients in the study had difficulty in planning, organizing and problem solving as measured by tests, observations and rating scales. They were alternately allocated to specific PST or to memory training (MT). The procedures were clearly specified and the patients allocated to the PST benefited to a significantly greater extent than those allocated to MT as measured by post-treatment assessment. A more recent study by Robertson *et al.* (2002) looked at limb activation treatment (LAT) for people with unilateral neglect. One group of

neglect patients received perceptual training alone while a second group received perceptual training plus LAT. The patients were assessed by a blind assessor three months and six months later on both functional measures and standardized tests. The results showed that left-sided motor function improved significantly more in the group receiving LAT. There is no doubt that although RCTs have a place in answering certain questions, we have to consider other methodologies, such as surveys, direct observations and single case experimental designs, in order to build up a broader picture of clinical effectiveness (Wilson, 1997).

A further difficulty with evaluating rehabilitation efficacy lies in the fact that standardized neuropsychological tests are often used as outcome measures, despite the fact that the purpose of rehabilitation is *not* to increase test scores and such tests are *not* the best outcome measures to use when evaluating cognitive or neuropsychological rehabilitation. Given that one of the major goals of rehabilitation is to enable people with disabilities to function as adequately as possible in their most appropriate environment, then information on changes in scores on standardized tests will not give us the information we require. JC, a densely amnesic patient known to us (Wilson *et al.*, 1997b), has shown no improvement on standardized tests over a 12-year period yet he lives on his own, is self-employed and completely independent thanks largely to his very good use of compensatory aids and strategies. By most standards these outcomes are very good indeed yet if standardized tests had been used as measures of success, JC would have been a complete failure instead of the outstanding success he is in real life.

Published evidence

Chesnut *et al.* (1999) were interested in the question of cognitive rehabilitation. They considered 114 articles related to cognitive rehabilitation in an attempt to answer a specific question: 'Does the application of compensatory rehabilitation enhance outcomes for people who sustain TBI?' Of the 114 potential articles only 32 reached the final selection to evaluate effectiveness, with the remainder being excluded for various reasons such as review articles, being purely descriptive, fewer than five subjects, and so on. Eleven of the 32 were RCTs with 5 measuring relevant health outcomes and 6 measuring intermediate outcomes. The authors of the report concluded that '… along with the small size of the studies and the narrow range of interventions studied, the lack of information about the representativeness of the included patients makes it difficult to apply the findings of these studies to cognitive rehabilitation practice generally' (p. 55). In other words, the RCTs reviewed did not tell us a great deal about the effectiveness of cognitive rehabilitation.

In a further report from the same study, the authors concluded that although the desired outcome of cognitive rehabilitation is improvement in daily function, many of the outcome measures are intermediate measures such as test scores (123 different tests of cognition were described in the studies). In reply to the question as to whether improvements on test scores predicted improvement in real-life function, the authors found that '. . . whereas there appears to be some relationship between intermediate measures and employment, the association is not strong'. We question the wisdom of using test scores at all, irrespective of whether they are intermediate or direct, and would recommend instead that rehabilitation therapists should consider the final outcome of their treatment. Whyte (1997) suggested that measures of outcome should be congruent with level of intervention, which makes sense. However, given that the ultimate aim of neuropsychological

rehabilitation is to enable people to participate in valued activities, then, whenever possible, outcome should be measured at this level.

It is possible to measure everyday functioning directly as evidenced by one of our own studies (Wilson *et al.*, 1997a), in which we wanted to know whether or not a simple pager could reduce everyday problems. Pagers are one of many compensatory aids that can be employed to reduce everyday problems in people with cognitive difficulties. We have carried out several studies to determine the efficacy of one particular type of pager, Neuro Page. In the first study (Wilson *et al.*, 1997a) we interviewed 15 clients and their families to identify the particular problems faced in real life. Each client chose the things he/she wanted or needed to remember and the time this should occur. These were then targeted for treatment. During a six-week baseline, 15 clients, each with a family member, recorded whether they remembered to carry out their own selected target behaviours. The average success rate for the group as a whole was 37% of targets remembered. Clients were then provided with a pager that was clipped on to a belt. The target messages (e.g. 'take your medication' or 'feed the dog') were sent to the individuals to remind them of their target behaviours. For the group as a whole, the success rate for targets remembered jumped to 85% correct during the 12 weeks the pager was used. After 12 weeks, the pager was withdrawn and clients were monitored for a further 3- to 4-week period. The success rate during this period was 74% correct, thus there was some drop back but performance was still well above the baseline. In fact some clients had learned their routines during the 12-week pager phase. Not only was there a significant increase in success rate between the first baseline and treatment for the group as a whole, but also every individual showed a statistically significant increase between the two stages.

Following on from this successful pilot study we went on to carry out a RCT using a crossover design whereby some clients were randomly allocated to a pager first and others were randomly allocated to a waiting-list first. After several weeks, there was a crossover in which those with a pager returned them and those on the waiting-list now received a pager. As before, we showed that the pager could significantly improve independence and everyday functioning (Wilson *et al.*, 2001).

We suggest that such direct measures of real-life behaviours are a very strong way of indicating changes brought about by cognitive rehabilitation strategies. We targeted the real-life problems identified by clients and their families; we measured these for several weeks thus having a control period (subjects being their own controls); we provided a clearly specified intervention; and we monitored clients once the pager was removed. Furthermore, we showed that the pager was effective across a wide range of people, diagnostic groups, intellectual abilities and time post-insult. It can be used once a day or many times a day; it is a flexible tool making a real difference to the quality of the everyday lives of the memory-impaired people in the study.

Tackling real-life targets and individualizing programmes within a specified framework is, we suggest, the way forward in cognitive rehabilitation. Clare and colleagues (Clare *et al.*, 1999, 2000, 2001) have also applied this principle to people with Alzheimer's disease. The client and family select the targets and then we find a way, using in this case errorless learning principles (described in Chapter 1), to teach new information.

The Chesnut *et al.* (1999) report said that there is an '. . . absence of strong and sufficient evidence for a direct effect of cognitive interventions on health and employment . . . and associations between performance on cognitive tests and post-trauma employment and productivity were inconsistent' (pp. 63 and 64). Our reply is that the question they posed, 'Is

cognitive rehabilitation effective?', is too broad to be answerable and we need to look at other ways of asking (and answering) the question. We can, for example, evaluate the effectiveness of some treatment procedures. We have already described some of the studies that have done this and there are others. Donkervoort *et al.* (2001), for example, found that patients with apraxia who received strategy training showed a bigger improvement in activities of daily living than did patients who received the usual occupational therapy training. Fasotti et al (2000) found that head injured patients who received Time Pressure Management Training to deal with information overload did better than patients receiving concentration training. These and other studies have been the subject of several other systematic reviews in recent years. Cicerone and colleagues conducted a review of the evidence base for cognitive rehabilitation (Cicerone *et al.* 2000), which was subsequently updated (Cicerone *et al.* 2005). Similarly, the European Federation of Neurological Societies reviewed largely the same literature (Cappa *et al.* 2005). Both groups took the approach of grouping studies for review in terms of which cognitive disorder was the focus of the intervention, though there were some differences in which disorders were included. Cicerone *et al.* looked at studies addressing the remediation of deficits of attention, visuo-spatial functioning, apraxia language and communication, memory and executive functioning and problem solving. Recognizing that some studies have examined interventions aiming to address several cognitive domains at the same time, Cicerone *et al.* reviewed such studies separately, and furthermore they had another category of studies of comprehensive-holistic cognitive rehabilitation. Cappa *et al.* reviewed studies of aphasia, unilateral spatial neglect, attention disorders, memory, apraxia and acalculia. Both reviews produced recommendations for clinical practice (using different systems of recommendation). The findings and recommendations from the reviews were relatively similar. Both reviews highlight that the evidence base remains relatively small, with very few good quality RCTs having been conducted. However, both also concluded that there was sufficient evidence that some clear recommendations for clinical practice could be made. For example, aphasia therapy based on cognitive-linguistic interventions was viewed as effective, though it was acknowledged that many studies in this area do not measure functional outcomes. There is evidence to support visual scanning training for unilateral neglect, with the suggestion that limb activation should be considered. For memory, strategy training is recommended for those with milder impairment, as is the use of external aids, including electronic aids, for those with moderate to severe deficits. Strategy training for attention deficits and apraxia is recommended. For problem solving and executive dysfunction, training approaches that emphasize development of self-instructional and verbal self-regulation skills are recommended. With regard to comprehensive-holistic cognitive rehabilitation programmes, Cicerone *et al.* concluded that, based on the available evidence, treatment in post-acute programmes of comprehensive-holistic cognitive rehabilitation that integrate cognitive and interpersonal interventions is recommended for people with moderate to severe TBI.

Other designs to evaluate the efficacy of rehabilitation

Single case and small group experimental designs are often useful in demonstrating the effectiveness of rehabilitation. Wilson (1999), for example, describes how a man who was completely unable to read following a gunshot wound was taught to read successfully 5 years later and achieved a reading age of 13 years. The value of single case experimental designs is that they allow us to evaluate an individual's response to treatment, to see if the client is

changing over time, and to find out whether any changes are due to natural recovery or to the intervention itself. In other words, we can tease out the effects of treatment from the effects of spontaneous recovery and other non-specific factors. Given that rehabilitation is planned for individuals, evaluation should take place at the individual as well as the group level, and the choice of individual or group study will again depend upon the kind of questions that need answering. For example, if we wish to find out whether a head injured person is benefiting from an attention training programme then we would need to employ a single case experimental design. If we wanted to find out how many people appeared to be benefiting from a particular procedure we would want to conduct a group study.

A group study would not necessarily inform us as to how any particular client within the group was or was not benefiting from any intervention, because each individual within the group is likely to have a different combination of deficits, is likely to be differently motivated, and is likely to have a different level of severity of impairment from all others in the group. Group studies average out performances so individual differences are masked. Single case experimental designs on the other hand avoid many of the problems inherent in group designs. They are often chosen specifically for their ability to evaluate an individual's progress through cognitive rehabilitation, and they are, of course, perfectly respectable as far as their scientific methodology is concerned (Hersen and Barlow, 1982; Kazdin, 1982; Gianutsos and Gianutsos, 1987). An individual study can provide information that is complementary to a group study, and indeed the two approaches should be held in equal regard. Large group studies are required when individual variations need to be shared out; single case (and small group) studies are preferable when each individual is monitored for a period of time, each acting as their own control, and when baselines are used instead of control groups.

A criticism often aimed at single case and small group studies points to their inability to generalize because their findings apply only to the individual subject. Such criticism is not entirely fair, and may be used by critics whose preferred methodology, large group studies, may not provide generalization because results are averaged and cannot therefore apply to individuals, most of whom will differ from the mean. We would argue that it is incorrect to assume that we cannot generalize from individual subjects. The whole history of neuropsychology provides examples of such generalization. From Broca's patient 'Tan' (Broca, 1861) to HM (Scoville and Milner, 1957) to other classic cases in neuropsychology (Code *et al.*, 1996, 2002), we have not only learned a great deal from individual patients but have also learned how to diagnose particular syndromes based on findings from these single cases.

Hersen and Barlow (1982) point out that 'To increase the base for generalisation from a single case experiment, one simply repeats the same experiment several times on similar patients, thereby providing the clinician with results from a number of patients.' (p. 57). Gianutsos and Gianutsos (1987) go even further by arguing that it is only through single case designs that generalizability can be established through systematic replication with controlled changes across variables that might be expected to affect generalization. In the light of such historical and contemporary findings we would argue that single case experimental designs, with their ability to allow us to evaluate generalization systematically, are to be embraced by those concerned with the efficacy of cognitive rehabilitation.

Establishing general principles

We have shown in this chapter that some therapeutic techniques in the field of cognitive rehabilitation are effective; and we suggest that single case experimental designs offer a

methodology that can be adapted more widely in the quest for establishing the effectiveness or otherwise of rehabilitation techniques. It is also possible to draw out some general principles that have been established in the field of cognitive rehabilitation. For example, the once widespread technique of trying to restore lost functioning through drills and exercises has been shown to be ineffective, at least in terms of its ability to generalize into real-life tasks (Robertson, 1990; Sturm and Willmes, 1991; Sloan and Ponsford, 1995). Repetition by itself is not an effective learning strategy (Baddeley, 1997). In the field of memory therapy it has been shown that distributed practice in the form of spaced retrieval (also known as expanding rehearsal) is a better method of learning than rote rehearsal (Camp, 1989; Moffat, 1989; Clare and Wilson, 1997). Visual imagery is also more efficacious for name learning than rote rehearsal, and pre-exposure to the faces to be learned is even more helpful (Wilson, 1987; Downes *et al.*, 1997). A strategy known as PQRST (see p. 86) is better at enhancing recall of written material than straightforward repetition (Wilson, 1987). Perhaps the most exciting recent work in new learning has been in the area of errorless learning described in Chapter 1. The effectiveness of this method has been fairly convincingly demonstrated with memory-impaired people (Baddeley and Wilson, 1994; Wilson *et al.*, 1994; Wilson and Evans, 1996; Squires *et al.*, 1997). Trial-and-error learning, or learning from our mistakes, is all very well when one has a reasonable episodic memory but, for those without adequate memory functioning, making a mistake can lead to the strengthening of an incorrect response.

Summary of the clinical effectiveness of cognitive rehabilitation

There is increasing evidence to support the view that rehabilitation can improve cognitive functioning (Robertson, 1999). Rehabilitation programmes can work through teaching people to compensate for their difficulties (Wilson and Watson, 1996); or through helping them to learn more efficiently (Baddeley and Wilson, 1994; Wilson *et al.*, 1994; Downes *et al.*, 1997) or through achieving restoration (or partial restoration) of functioning resulting from plasticity and exercising (Robertson *et al.*, 1995; Sturm *et al.*, 1997; Robertson and Murre, 1999). Robertson (1999) believes that restoration may be possible after relatively small lesions while compensatory processes are more likely to underlie recovery from larger lesions. While this idea is similar to that offered by Poppelreuter (1917), Robertson based his views on connectionist models aimed at predicting recovery. Plaut (1996) also uses a connectionist model to predict recovery and argues that the degree of relearning and generalization varies considerably depending on the lesion location, and this in turn has implications for understanding the nature and variability of improvement following brain injury. Plaut's model appears to address retraining rather than compensation, although as both Zangwill (1947) and Luria (1963) believed during the Second World War, both are important aspects of rehabilitation.

Evidence for the cost-effectiveness of rehabilitation

Most countries are interested in whether or not rehabilitation is worth the effort in economic as well as clinical terms (McCarthy, 1999; Diller, 2000; Prigatano and Pliskin, 2002). Wood *et al.* (1999) suggest that international opinion about the clinical- and cost-effectiveness of neurorehabilitation is divided, with considerable scepticism seen among

neurologists, neurosurgeons and others, but with enthusiasm among some staff providing such rehabilitation. Wood *et al.* discuss two types of costs, direct and indirect. Direct costs refer to the provision of treatment and indirect costs refer to social burdens such as time off work, sickness benefits and so forth. Bearing these categories in mind, let us consider whether rehabilitation is cost effective?

In one American study of 145 brain injured patients (Cope *et al.*, 1991), the estimated savings in care costs following rehabilitation for people with severe brain injury was over £27 000 ($40 500) per year. The number of people requiring 24 hours per day care dropped from 23% to 4% after rehabilitation. A Danish study (Mehlbye and Larsen, 1994) reported that spendings in health and social care for patients attending a non-residential programme were recouped in five years. The costs of not rehabilitating people with brain injury are also considerable given the fact that many are young with a relatively normal life-expectancy (Greenwood and McMillan, 1993). Cope (1994) suggests that post-acute rehabilitation programmes can produce sufficient savings to justify their support on a cost–benefit basis. On a slightly different theme, a study by West *et al.* (1991) claimed that people with TBI who had attended a supported work programme earned more than the programme costs after 58 weeks of supported employment. Furthermore, after two and a half years there was a net gain to the taxpayers who had ultimately funded the service. This did not include the indirect costs such as savings from family members who were able to return to work. Three case studies reported by Bistany (1988) estimated annual and lifetime costs with and without a specialized rehabilitation programme and the estimated lifetime saving was over one million US dollars for each of the three individuals.

Wood *et al.* (1999) wanted to establish the clinical- and cost-effectiveness of a post-acute neurobehavioural community rehabilitation programme provided for 76 people surviving severe brain injury. The majority had sustained their injuries more than two years prior to admission and all had spent at least six months in rehabilitation. In terms of improved social outcomes and savings in care hours, it was found that the most cost-effective provision was to provide rehabilitation within two years of head injury. Nevertheless it was still worthwhile in terms of clinical- and cost-effectiveness to offer rehabilitation to those who were more than two years post-insult.

It is also possible to estimate the costs of separate components of a rehabilitation service. For example, the pager referred to above has been shown to save money for the UK National Health Service and Social Services (Wilson and Evans, 2002). One client (described originally by Evans *et al.*, 1998) used to spend one week every three months in respite care to give her family a break. Her local health authority paid for this at a cost of £3500 per week, i.e. £14 000 per year. Since having the pager she has never needed respite care, so over a 6-year period her health authority has saved £84 000. Another client on the same system seen 7 years post head injury learned to live independently with the pager (Wilson *et al.*, 1999). After being involved in a 16-week research project (baseline for 2 weeks, pager for 7 weeks and post-baseline monitoring for 7 weeks), the young man moved into his own apartment with 24-hour care provided by the Social Services. An estimate of the costs for the carers (based on Wood *et al.*, 1999) was £7 per hour, i.e. £168 day, £1176 per week and £61 152 per year. Within 3 months, the man was able to manage with one carer for 12 hours rather than two carers over 24 hours, thus halving the costs to the Social Services.

Once the research on the pager was completed the health authority set up a clinical service for people throughout the United Kingdom. The cost of providing this is £60 per

client per month. This covers the hire of a pager, air time, a contribution to the salary of the staff member running the programme, overheads and a royalty to the developer of the system. Although this is a considerable amount of money to find for some families, most of the clients are funded by health or social services. In the long term, money is likely to be saved in a number of ways, not only through reduced stays in hospital and a reduction in the number of carers, but also because medication is taken reliably, hospital visits are missed less often and family members can return to work. A survey of the first 40 people to enter the service (Wilson *et al*., 2003) showed that 26 health authorities from England and Scotland were referring people for the pager, all had obtained funding, and many diagnostic groups were represented with TBI being the largest single group. Of the 33 different types of message sent each week the most frequent were reminders to take medication; 514 medication messages were sent out each week followed by 380 messages referring to orientation (e.g. reminders about which day it was and what time it was) and 193 concerned with food (e.g. making packed lunches, eating breakfast etc.). Among the least frequent messages sent each week were concerned with transport (e.g. phone for taxi) with eight of these types of message sent each week and with finances (e.g. checking bank balances) with only four of these messages going out each week. One man only requested two messages a week and at the other extreme one woman requested 147 messages per week. It is encouraging that access to assistive technology including the NeuroPage service is now recognized in the United Kingdom in documents from the National Service Framework for Long Term Conditions (Department of Health, 2005) and by the Medicines and Healthcare Regulatory Agency (2004).

Although much needs to be done, there is growing evidence that neuropsychological rehabilitation programmes are effective economically while also contributing significantly towards improving the quality of life of those requiring clinical assistance in their daily lives.

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Chapter 3

Goal setting as a way of planning and evaluating neuropsychological rehabilitation

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Introduction

How should we plan and evaluate rehabilitation? We will argue here that the most appropriate way to plan, direct and measure the success of rehabilitation is through the process of goal setting. If neuropsychological rehabilitation is ultimately concerned with enabling people with brain injury to participate effectively in valued activities, then it follows that we should measure the outcome of an individual's rehabilitation programme in terms of whether or not the programme enables that individual to achieve his/her personal goals. If outcome is defined in terms of personal goals, then it makes sense that these goals should be the central focus when planning the specific components of a rehabilitation programme.

In relation to evaluation of outcome, if one is evaluating a specific treatment intervention that aims to improve a particular cognitive function, then it is useful to have an assessment of that cognitive function as an outcome measure. However, even when evaluating a specific treatment it is important to measure the extent to which the intervention improves the client's functioning in his/her everyday life. Some studies aiming to evaluate cognitive or neuropsychological rehabilitation programmes use standardized neuropsychological tests as their main, or only, outcome measure (see, for example, the studies reviewed by Carney *et al.*, 1999). We would argue that use of such tests, on their own, either to plan or to evaluate rehabilitation programmes is wrong. It is wrong to use them in order to plan programmes because the purpose of rehabilitation is not to improve test scores per se and because the relationship between test performance and real-life skills is only modest; it is wrong to use them to judge the outcome or effectiveness of rehabilitation for the same reasons. Although, these tests provide a profile of a person's cognitive strengths and weaknesses, they do not tell us a great deal about how people with neuropsychological deficits cope in everyday life. Nor do they tell us what brain injured people and their families hope to achieve and what is important for them. If test scores reflected competence in real-life skills, then it would be a different story, but the relationship between test scores and real-life functioning is unclear (Sbordone and Long,

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1996). There is, at best, an indirect relationship between the two and, at worst, there is no relationship at all (Wilson, 1996). Take the example of 'Jay' (Wilson, 1999), a young man with a severe memory impairment who manages to live alone completely independently. He holds down a job and completes his own tax forms. He can do all of these things because he uses compensatory strategies very efficiently and because of excellent organization and planning abilities. Almost anyone working in rehabilitation would describe 'Jay' as a rehabilitation success, but if standardized tests were used to measure this success, then 'Jay' would be a failure as he scores zero on any test of delayed memory. This is not to say that neuropsychological tests are unimportant in rehabilitation. Of course they are important. They allow us to build up a map of each individual's strengths and weaknesses, they allow us to avoid strategies that are cognitively impossible, they enable us to ask specific questions that are clinically, scientifically and theoretically interesting but they are not the major tool for planning programmes or for determining rehabilitation success. We argue that goal setting provides a means of planning rehabilitation programmes and measures of goal achievement provide an important means of evaluating the effectiveness of rehabilitation programmes.

Outwith rehabilitation there is a long history of research on the use of goal setting in business and sporting arenas. Hart and Evans (2006) discuss this literature and its relevance to brain injury rehabilitation. Locke and Latham (2002) summarized findings from more than 30 years of studies and several meta-analytic reviews of goal setting and its application, principally in commerce, education and sport. They conclude that there is strong evidence that goal setting improves performance (be it business-related performance such as sales or factory productivity, or sporting success). They suggest that there are several mechanisms by which goal setting influences behaviour. Goals serve a directive function, directing attention toward goal-relevant activities and away from goal-irrelevant activities. Goals have an energizing effect, with more demanding goals leading to greater effort than less demanding goals. Goals also affect persistence, with hard goals leading to prolonged effort. Finally, goals are thought to lead to the arousal, discovery and use of task-relevant knowledge and strategies.

The work of Locke and Latham and others has established that specific goals lead to better performance than vague, 'do your best' goals. Although the evidence for this effect in brain injury rehabilitation is limited, there are suggestions that the same principle might apply. As a very simple example of goal setting, Gauggel and Fischer (2001) randomly allocated 45 people with brain injury into 2 groups. Each group was assessed on the Purdue Pegboard Test. One group was given a general goal to 'Do your best'. The other group was set a specific goal 'Try to increase your speed by 20 seconds'. Those given the specific goal performed significantly better than the group set the general goal. Gauggel and colleagues have found similar results with other tasks including mental arithmetic (Gauggel and Biliano, 2002) and reaction times (Gauggel *et al.* 2001).

Goal theory suggests that combining long-term goals with a series of short-term goals is more effective than just long-term goals (Latham and Seijts, 1999). Feedback in terms of progress towards long-term goals is considered an important moderator of goal achievement, and for clients with brain injury and significant cognitive impairment regular feedback is likely to be critical. The use of short-term goals allows for clear markers of progress towards long-term goals to be set. This allows the client to experience a sense of the gap between their current situation and their goal diminishing. In terms of Carver and Scheier's (1990) Control Theory model, reducing the discrepancy between current state and goal state is seen as critical in reducing emotional distress. Within the realm of

rehabilitation, a study by McGrath and Adams (1999) of 82 patients in rehabilitation suggested that progress in rehabilitation (through goal setting and achievement) was associated with reductions in anxiety.

Another moderator of goal achievement is goal commitment (Locke and Latham, 2002). It has been shown, outside of rehabilitation, that it is not essential that people have participated in the goal setting process as long as the rationale for the goal is clearly understood and accepted. But probably the easiest way to ensure that a client is committed to a goal is for the client to have participated in setting the goal. Clearly, the importance of the meaning or nature of the goal is important – clients will become frustrated or distressed if they are directed towards a goal that clashes with what is important to them. We often see this when working with clients who appear to resist and reject potentially helpful strategies. Protests may include that to use the strategy would be 'giving in' to the injury. However, clients do not always possess the ability to communicate such emotional states easily. Conway's (2005) self-memory model makes explicit links between current goal directed activity and identity. A recent study of identity following brain injury (Cantor *et al.*, 2005) highlighted how self-discrepancy in terms of ratings of current self and pre-injury self predicted psychological distress. Gracey and colleagues (Gracey *et al.*, 2008) report a method being used at the Oliver Zangwill Centre for Neuropsychological Rehabilitation based on personal construct psychology (Kelly, 1955) to assess the ways in which acquired brain injury clients make sense of themselves post-injury. In addition to changes in abilities (e.g. cognitive difficulties) and emotions (e.g. nature and intensity of emotions), clients identified constructs for making sense of themselves in relation to others, in relation to pre-injury, and in the context of specific activities. Thus it becomes apparent that perhaps unconscious representations of personally salient goals may be under threat post-injury. The setting of carefully identified and personally meaningful goals in itself may represent a very practical form of psychotherapy throughout rehabilitation.

For some clients, cognitive impairment, particularly memory impairment, will impede their ability to remember goals and/or their rationales. They may therefore need to be supported to remember them. Hart *et al.* (2002) used an external memory aid, a Voice Organizer, onto which clients recorded their goals. The Voice Organizer prompted them to review the goals from time to time and there was evidence that this led to better recall of therapy goals.

Self-efficacy is also important to goal commitment. If someone believes they can achieve a goal they are more likely to work towards it, than if they do not believe it. Here again the use of short-term goals and frequent feedback on progress will be useful in increasing a sense of self-efficacy and so increase motivation to work towards the goal.

Goal theory therefore suggests that rehabilitation productivity, or outcome, should be greatest when specific, challenging goals are set. The rationale for goals should be clear to the client, preferably by involving them in setting the goal, or providing an understandable rationale for the goal. Clients should have long-term as well as short-term goals. There should be frequent opportunities for feedback on progress. Clients may need to be supported to remember the goals and their rationales as well as the progress made towards the goal.

Goal planning in practice

McMillan and Sparks (1999) remind us that goal planning has been used in rehabilitation for a number of years with various diagnostic groups including people with cerebral palsy, spinal injuries, developmental learning difficulties, psychiatric problems, sports injuries and

acquired brain injury. It has also been used in industry and other non-clinical settings. Because goal planning is simple, focuses on practical everyday problems, is tailored to individual needs and avoids the artificial distinction between many outcome measures and real-life functioning, it is used increasingly in rehabilitation programmes.

Houts and Scott (1975) and McMillan and Sparkes (1999) put forward several principles of the goal planning approach. First, the patient should be involved in setting his/her goals. Second, the goals set should be reasonable ones and client-centred. Third, the patient's behaviour when a goal is reached should be described. Fourth, the method to be used in achieving the goals should be spelled out in such a manner that anyone reading the plan would know what to do. In addition, goals should be specific and measurable and have a definite time deadline. In most rehabilitation centres, long-term goals are those the patient or client is expected to achieve by the time of discharge from the programme while short-term goals are the steps set each week or fortnight to achieve the long-term goals.

McMillan and Sparkes (1999) describe the process of goal planning as carried out at The Wolfson Rehabilitation Centre in London (other programmes deviate from this basic design to a greater or lesser degree; see, for example, Wade (1999a) for a description of the approach used at Rivermead Rehabilitation Centre in Oxford). Typically, a chairperson is allocated. This person should chair all meetings, keep these within an agreed time limit, ensure the team members are clear about the aims of admission and the length of stay, be an active member of the rehabilitation team and ensure documentation is complete. The chairperson should also ensure good communication between all relevant parties, attend case conferences, co-ordinate reports, encourage clients, relatives and staff members to be realistic and make clear arguments to the relevant people for changes to the discharge date. Following a detailed assessment period, the first goal planning meeting is held, a problem list drawn up and potential long-term goals identified. These are then discussed with the client and the family and the final goals are negotiated and agreed. Both long- and short-term goals are documented. If it is considered helpful, the client and the family members involved are given a copy of the short-term goals to be achieved by the following week or fortnight. Progress is reviewed every week or every 2 weeks in a 30-minute meeting with the rehabilitation team. Further short-term goals are set and, if necessary, additional long-term goals are added. If any long- or short-term goals are not achieved or are only partially achieved, the reasons for this are recorded. There are four main categories for failure to achieve a goal: (1) client/patient or carer reasons (e.g. client unwell), (2) staff member reasons (e.g. staff member absent through illness), (3) reasons due to internal administration (e.g. transport failed to arrive) and (4) reasons due to external administration (e.g. funding withdrawn by rehabilitation purchaser).

In our centre, the Oliver Zangwill Centre, goals are negotiated between the client, the family and the rehabilitation staff during an initial two-week detailed assessment. Wilson *et al.* (2002) describe a successful goal planning approach for a man who sustained both a head injury and a stroke. This man, Peter, and his programme are described in Chapter 13. One of the main outcome measures in our programme is the percentage of goals achieved. We use this alongside more traditional outcome measures such as return to paid employment, independent living and psychosocial measures. These measures will be referred to in Section 3 of this book, where we present case studies.

The advantages of a goal planning approach are spelled out by McMillan and Sparkes (1999). First, it is simple. Second, it makes the aims of the admission clear. Third, it is client-centred. Fourth, it encourages team cohesion. Fifth, it incorporates a measure of

outcome. Sixth, it removes the artificial distinction between measurement of outcome and client-centred activity. Seventh, it is useful for auditing purposes and eighth, it does not require extensive staff training. There are some disadvantages too, for example goal planning does not provide systematically collected data on all possible outcomes, it is possible to make the goals too easy and success depends on a good and experienced chairperson. These problems can be overcome, however. First, goal planning should not be used as the sole outcome measure so other outcomes and data can be collected concurrently with data from goal planning. Williams *et al.* (1999) use a number of measures to look at the reduction of limitations and the increase of activities and participation in society. Second, staff training can reduce the problems with an inexperienced chair or team members. We run an apprenticeship system whereby new members of staff shadow an experienced member for several weeks before taking on the chairpersonship of a goal planning meeting/programme. Third, goal attainment scaling (GAS; see Malec, 1999) can be used to weight the goals to make them more comparable.

Malec (1999) discusses GAS in some detail. It is a method of measurement introduced in 1968 by Kiresuk and Sherman to evaluate health programmes. It has been used in community mental health centres, psychiatric hospitals, in-patient programmes, substance abuse programmes, family therapy and geriatric programmes as well as brain injury services. It allows us to quantify the achievement of highly individualized goals that are the focus of rehabilitation. Once goals have been satisfactorily negotiated, weights can be applied to each of the goals to reflect their relative importance. Not everyone, however, believes in the wisdom of weighting goals in rehabilitation settings. Grenville and Lyne (1995) for example say it is not a good idea as goal setters are less likely to agree about the weights or the priority of goals than they are about the nature of the goals. Furthermore, although it may be desirable to have goals of equal weights when comparing individuals within a programme or when comparing across programmes, at a personal level it is not a bad idea to have some goals that are relatively easy to achieve so as to encourage the individual patient and the staff members and improve morale. As the old saying goes 'nothing succeeds like success'. Wade (1999b) recommends that goals should be set at a variety of levels.

Goal attainment scaling, according to Malec (1999), also requires the setting of a deadline by which the goal should be achieved and is thus similar to the goal setting described above. Where GAS differs from the basic goal setting programme is that one should state the 'expected' level of outcome (set at zero) and then one could determine whether achievement is at, above or 'below' this expected level. According to Malec (1999), the 'expected' level is 'a level of goal achievement that is realistic in the sense that the client can achieve this outcome in the specified time with a reasonable, but not exceptional degree of effort' (p. 257). The example provided is use of a memory notebook. The 'expected' level is that the client should use the book 50–74% of the time to record information to be remembered. If achieved this would score 0. If the client uses the book 25–49% of the time the score would be minus 1, less than this would score minus 2. If the book is used 75–89% of the time the score would be plus 1 and anything above this level would score plus 2. Malec recognizes the limitations of this approach, for example most systems would not be sensitive enough to distinguish between 49% and 50% of the time a notebook was used to record information to be remembered. Nevertheless, Malec reports data suggesting that GAS is more sensitive than other health measures at evaluating outcome. He also provides a formula for converting GAS scores to T scores and

demonstrates that GAS T scores tend to be normally distributed. He suggests that GAS is a valuable methodology in rehabilitation because (1) it allows the monitoring of progress in time-limited programmes, (2) it helps structure team meetings, (3) it helps in the planning of ongoing rehabilitation and decision-making, (4) it ensures concise, relevant communication to the client, significant others, referrers and funding sources, (5) it helps guide the delivery of social reinforcement, (6) it is a means of evaluating the programme, (7) it encourages more accurate self-awareness and (8) it helps to redevelop the capacity for goal setting in people with impairments of higher order metacognitive abilities in people with brain injury.

Beaumont *et al.* (1999) also support goal setting in neuropsychological rehabilitation, arguing that standard measures of change for what we are trying to change may not be available; comparisons across individuals are difficult both because of the variability in clients' needs and the variability of the personal programmes and because of the need to determine the context in which the outcome should be measured, for example, in the rehabilitation unit, after discharge, at work etc. In addition, any measurement needs to reflect the interdisciplinary nature of the intervention so measures used by psychologists may be different from those used by other therapists. Structured goal setting certainly avoids many of these problems.

Evidence for the effectiveness of goal setting

We have argued that goal setting makes good sense as a method of planning and evaluating outcome in rehabilitation. We have referred to the large amount of evidence that goal setting is effective, but, as Wade (1998) pointed out, there has been much less research on the benefits of goal setting in rehabilitation contexts. Wade (1998) concluded at that time that, 'there is probably sufficient evidence to support the continuing use of goal planning in those teams already using goal planning. However, it is less certain that the evidence is sufficiently strong to require a change to goal planning if it is not already being undertaken … ' (p. 275). A recent systematic review of studies of the effectiveness of goal setting (Levack *et al.*, 2006) drew a similar conclusion to Wade. A more recent study undertaken by Holliday *et al.* (2007), and published after Levack *et al.*'s review, compared 'usual practice' goal setting with 'increased participation' goal setting in an in-patient neurological rehabilitation unit. The study looked at the impact of increased participation in goal setting on outcome (on standard measures such as Functional Independence Measure (FIM), London Handicap Scale and General Health Questionnaire (28 item version: 28)). They also measured patients' sense of involvement in the goal setting process, the relevance of goals to them and also patients' overall satisfaction with the rehabilitation process. 'Usual practice' did involve goal setting whereby goals were set by the treating therapists following assessment and discussion of goals with the patient. Increased participation focused on use of a 'goal setting workbook' completed by the patient in part prior to the admission (with help of family or friends) and then completed by the patient together with the therapist. The workbook asks the patient to prioritize activity and participation domains and to identify specific tasks to work on in rehabilitation. Holliday *et al.* found that there was no difference in terms of functional outcome between the two approaches, but that patients in the increased participation group reported that they felt they had more choice in terms of goals set, the goals were more relevant and their level of overall satisfaction with the rehabilitation process was higher than those in the usual

practice group. This study highlights the fact that studies of goal setting should at least include, if not focus on, measures of the patients' experience of the rehabilitation process. Holliday *et al.* note that delivering care in a manner that is meaningful for the individual is 'more likely to lead to long term 'adherence' or … result in the transfer of newly learnt skills to the individual's own home and community'.

Goal setting in other situations

Even in circumstances or situations where a formal goal planning programme is not in operation, it is possible to use goal setting to plan and evaluate treatment programmes. Whenever someone requires help with a problem whether or not it has resulted from an insult to the brain, it is, as a rule, easier to operationally define the problem and treat a functional manifestation of a deficit than it is to treat an impairment measured by a test or a more general difficulty. Thus it is not helpful to have as a treatment objective 'improving memory'; 'reducing an attentional deficit' or 'improving motivation'. Success is more likely to be achieved if a specific goal is set such as 'Teach Mr Brown to check his notebook after each meal', 'Paul should work at a task in occupational therapy for 15 minutes before leaving his seat' and 'Document improvement so that Linda can see she is making progress.' In these circumstances, it is possible to take a baseline, measure performance and determine whether change is taking place (Wilson, 1991). One of the arguments sometimes made against this approach is that it is treating the symptom rather than the cause. Although this argument may be true, there is often little evidence that treating the underlying cause gets us anywhere. In memory rehabilitation, for example, there is no convincing evidence that treating the underlying deficit results in any general improvement of memory (Glisky and Shacter, 1986; Wilson, 1995). Furthermore, there is nothing to stop people trying to achieve general improvement by stimulation or exercise (which are the usual strategies employed when one is treating the underlying problem), alongside a goal setting approach. One may have to be careful about the measurements used if two approaches are used simultaneously, but to move people forward and to reduce everyday problems, it is more fruitful to set and achieve goals. Some goals lead to a general improvement in any case. Jenny, for example, described in Wilson (1999), completely lost the ability to read following a severe head injury sustained in a horse-riding accident. Her reading remediation began with one goal namely to learn to read the letter 'Y'. This took several weeks, other letters were introduced one at a time, then letter combinations were taught (e.g. 'oa', 'igh'). Eventually Jenny learned to read most words and achieved a reading age of 12.5 years. She also began to read for pleasure. In this case a small-step-goal-oriented programme did, at least partially, remediate the underlying deficit.

It is possible to set goals and evaluate rehabilitation in a manner that is both scientifically respectable and clinically relevant. Take, for example, the work of Clare and her colleagues (Clare *et al.* 1999, 2000, 2001). They worked with people with Alzheimer's disease (AD). In the first study, a man who had been diagnosed with AD six years earlier, wanted to relearn the names of his friends at a bowls club. Each name became a separate, short-term goal. The man was taught the names one at a time. Initially the man worked from photographs of his friends. A procedure was used that combined three rehabilitation strategies, namely errorless learning, vanishing cues and spaced retrieval (otherwise known as expanding rehearsal). Errorless learning was described in

Chapter 1 (Wilson *et al.* 1994). Vanishing cues (Glisky *et al.*, 1986) is a method in which cues or prompts are gradually faded out. For example when the man was learning the name Caroline he first copied the entire name then copied the name with the last letter missing (Carolin_) and had to complete the last letter; then the last two letters were omitted (Caroli–) and so forth. Spaced retrieval or expanding rehearsal (Landauer and Bjork, 1978) is a strategy which gradually extends the retention interval. Thus information is presented and tested immediately; it is then tested after a brief delay of perhaps a few seconds then after a slightly longer delay and so forth. Together with these three methods a multiple baseline across behaviours design was used to separate practice from treatment effects (Wilson 1987). After the initial learning phase, generalization was measured: the man was taken to his club with the photographs and he was requested to find the person and introduce the person by name to the psychologist. At this point the man was close to 100% success. At a three-month, six-month and nine-month follow-up, he was always 100% successful despite the fact that the AD was progressing. In the 2000 study, Clare *et al.* carried out a small group study with people with AD and demonstrated that learning of useful everyday information was possible. Each patient was significantly better after treatment than during the baseline period and some of these maintained improvement at follow-up. One of the important things about these studies is that clients and families selected their own targets or goals. The first man wanted to relearn the names of his colleagues, another person wanted to learn to use a wall calendar, another the birthdays of her grandchildren and so forth. It is much better to work on the things clients want help with rather than some experimental material with little inherent interest to the person with the disability. Hardly any cognitive rehabilitation programmes do this, however. If proper baselines are taken and the appropriate data recorded we can plan and evaluate our rehabilitation programmes in a scientifically respectable way.

One can sometimes hear the argument that these are 'only' single case studies and we need larger numbers to convince people of the value of rehabilitation. To combat this point of view, we would repeat what we said in Chapter 2, i.e. first, single case designs are perfectly acceptable and respected designs (Hersen and Barlow, 1976; Kazdin, 1976; Wilson, 1987). Second, it is possible to generalize from such studies; one simply repeats the results with other patients. Indeed Gianutsos and Gianutsos (1987) argue that this is the best way to ensure generalization as large group studies give us averaged results and no one individual is likely to be similar to this group average. Nevertheless, there are sceptics who only accept results from larger samples so the third point is that single case designs sometimes pave the way to a larger, randomized control study where it is also possible to follow a goal planning approach. This, for example, is what happened in our NeuroPage studies described earlier. We started with several single case studies, combined these into a small group study and then moved on to a randomized control study.

Conclusion

In conclusion to this chapter, we recommend goal setting as one of the best ways to structure rehabilitation for individuals and ensure one is dealing with clinically relevant problems. This approach should also be incorporated into the evaluation of rehabilitation success. As Wade (1999b) said 'Good rehabilitation practice should set meaningful and challenging but achievable goals' (p. 41).

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Chapter 4

The Oliver Zangwill Centre approach to neuropsychological rehabilitation

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Introduction

The Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation opened in 1996 and was modelled on the American holistic programmes developed by Yehuda Ben-Yishay and George Prigatano. It was named after Oliver Louis Zangwill, Professor of Psychology at Cambridge University between 1954 and 1984. He was also a pioneer of brain injury rehabilitation in Great Britain during the Second World War when he worked in Edinburgh with brain injured soldiers. The Centre follows many of the principles laid down by Ben-Yishay (1978), Prigatano *et al.* (1986) and Christensen and Teasdale (1995), and is also significantly influenced by the critical 'scientist practitioner' model of clinical psychology adopted in the United Kingdom.

A holistic approach to brain injury rehabilitation '. . . consists of well-integrated interventions that exceed in scope, as well as in kind, those highly specific and circumscribed interventions which are usually subsumed under the term "cognitive remediation"' (Ben-Yishay and Prigatano, 1990; p. 40). The holistic approach recognizes that it does not make sense to separate the cognitive, emotional and social consequences of brain injury as how we feel and think affects how we behave. Ben-Yishay's (1978) model follows a hierarchy of stages through which the patient or client should work in rehabilitation. These stages are engagement, awareness, mastery, control, acceptance and identity. Individual and group sessions are provided to enable patients to work through these stages.

The origins of the OZC go back to 1993 when one of us (BAW) spent several weeks at Prigatano's unit in Phoenix Arizona. The idea to open a similar centre in the United Kingdom started during this visit. In April 1993 negotiations began with the local National Health Service Trust. With some false starts and setbacks, and backing from the Medical Research Council, it took three years to get permission for the Centre to go ahead. We appointed the first member of staff in July 1996, we arranged for three months of staff training and planning programmes before admitting our first clients and officially opened in November 1996.

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The structure of the Oliver Zangwill Centre

Like the Phoenix unit, ours is a non-residential centre. Clients come four or five days a week for several weeks (the intensive phase) and then begin the reintegration phase during which they come for two to three days a week for several weeks. During this time they are beginning to re-enter the world of work, further education and greater independence. Examples of how this is done can be found in the chapters on individual clients later in the book (Chapters 13–21). We aim to provide high quality rehabilitation for the individual cognitive, social, emotional and physical needs of people with non-progressive brain injury and also to meet the needs of the families. The ultimate aim is to promote the maximum level of independent functioning in both the home and the community and in productive work. Because the Centre is a partnership between the local National Health Service Trust and the Medical Research Council, we also seek to apply the latest research findings, evaluate our service and investigate ways to improve neuropsychological rehabilitation.

We accept people with non-progressive brain injury aged between 16 and 60 years. Most have sustained a traumatic brain injury but we also have clients who have had a stroke, encephalitis, meningitis, anoxic brain damage or other acquired brain injuries. Most of our clients are at least two years post-insult although a few come as early as six months post-injury and a few are five or more years post-insult. As a rule, they have had some in-patient rehabilitation and out-patient rehabilitation but will not have had an intensive, comprehensive, holistic, rehabilitation programme. Attendance at the OZC is often seen as the last chance to help people try to achieve their optimum level of functioning. We have up to eight clients at any one time with somewhere around a one-to-one staff–client ratio. Although this may be seen as unusual and a privileged position to be in, it is probably the reason for our success. The staff–client ratio also provides the resources to be more thorough in planning and conducting our clinical work in order that innovative interventions can be developed and then disseminated to others working in the field. By the end of their stay, we expect clients to demonstrate an understanding of their brain injury and the consequences of this for everyday life. They should also demonstrate an awareness of their individual strengths and weaknesses resulting from the brain injury. All clients are expected to develop and implement strategies to compensate for the specific consequences of the insult to the brain, be able to monitor their own performance in using these strategies and carry these over from the Centre to their own community settings. Many clients describe feeling different as a result of their programme, like some of their old self has come back, along with a developing new sense of who they are post-injury. We help relatives and significant others to develop a shared understanding with and support the person with brain injury, to help understand the relationship between brain injury and its consequences for the brain injured individual and for themselves.

The staff team at the OZC is comprised of three clinical psychologists, two and a half occupational therapists, one and a half speech and language therapists and a physiotherapist, all of whom have specialized in rehabilitation with people who have sustained a brain injury. In addition we have two psychology assistant practitioners (psychology graduates), a rehabilitation assistant and an administrative team. A research assistant post is filled when external funding is available. There are usually other people around working on research projects, or students or visitors from overseas gaining experience. The clinical manager is not a medical person but one of the permanent team. A psychologist, a speech and language therapist and a physiotherapist have all held this position. We have a neuropsychiatrist who

runs a clinic once a fortnight and a consultant neurologist who attends as required. It should be remembered that our clients are medically stable so we do not need a medical person on site all the time. There is a minor injuries unit elsewhere in the hospital and we can call on the staff there, for example, when one of our clients has a seizure. There is also a local primary care physician who will see our clients if needed.

The Oliver Zangwill Centre Clinical Programme

Organizing rehabilitation: a 'Y-shaped' model of the rehabilitation process

Organizing multiple models and different professional orientations at the same time as being sensitive to the individual client and their family, and possibly other professionals, presents a considerable challenge. By drawing on emerging literature regarding identity change and rehabilitation, the existing holistic models, goal setting models, educational models and models of organizational performance and group process, we have begun to develop systems for organizing our rehabilitation endeavour. One example of this is provided in Chapter 1 (Figure 1.2), the framework we use for sharing assessment results to help make sense of the client's current situation.

In attempting to address the challenge of providing interdisciplinary rehabilitation where clients' domains of difficulty interact, the approaches used for organizing goal setting and co-ordination of work targeting disrupted processes (e.g. relating to cognition or emotion) with work on functionally oriented, meaningful goals (e.g. returning to work) have evolved. By drawing on the emerging research mentioned earlier we have developed a 'Y-shaped' model to aid mapping the interdisciplinary process of teamwork onto the change process undergone by the client. The two branches of the 'Y' were initially conceptualized as representing work at the 'impairment' and 'social participation' levels respectively. We have developed this so as to emphasize the process of change for the client in terms of resolution of the psychological (meaning, identity, understanding, expectations, interactions, processes) and social (roles, activities, contexts, relationships) discrepancies, and this is shown in Figure 4.1. The model is very much work in progress measured in large part by its utility in helping the team work in an integrated way, that makes sense to the clients, and is sensitive to their personal adjustment process.

The model takes as its starting point the notion that, based on research into identity change post-injury (Tyerman and Humphrey, 1984; Nochi, 1998, 2000; Cantor *et al.*, 2005), there is a discrepancy between pre-injury self-representations (i.e. expectations, abilities, goals, values etc.) and their post-injury reality (e.g. disinhibited, forgetful, not at work). Goldstein (1959) and Ben-Yishay (2000) have described a 'catastrophic reaction' that is an emotional response to the 'threat' of such post-injury changes. We can begin to understand some of our clients' behaviour in terms of attempts to manage the distress of this threat, often through avoidance, be that behavioural, cognitive, emotional or social, and to try to maintain continuity in their sense of self. The top of the 'Y' represents the degree of discrepancy at the start of the programme. Some clients experience this discrepancy, find it intensely distressing and can reflect on this, others may successfully avoid or suppress this distress, or are cognitively limited so that they are unable to report changes. It may be that under such circumstances discrepancy is more likely to be played out in interactions with others. This may take the form of relatives contesting the brain injured person's account,

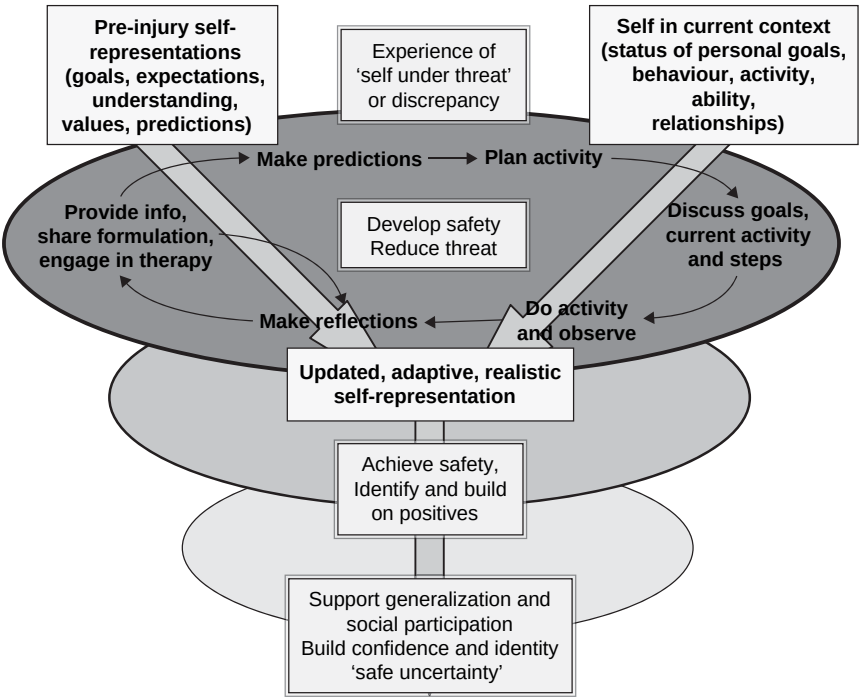
Pre-injury self-representations (goals, expectations, understanding, values, predictions)
Experience of 'self under threat' or discrepancy
Self in current context (status of personal goals, behaviour, activity, ability, relationships)
Make predictions
Plan activity
Provide info, share formulation, engage in therapy
Develop safety Reduce threat
Discuss goals, current activity and steps
Make reflections
Do activity and observe
Updated, adaptive, realistic self-representation
Achieve safety, Identify and build on positives
Support generalization and social participation
Build confidence and identity
'safe uncertainty'

Figure 4.1 The 'Y-shaped' process model of rehabilitation. The green arrows that form the 'Y' show the process of reducing discrepancy towards an integrated sense of social and personal identity. A rehabilitation process influenced by holistic models (green boxes) is shown together with processes of identity change based on social and personal self-discrepancy (yellow boxes), and experiential learning as applied in behavioural experiments in cognitive behaviour therapy (pink ellipses and arrows). See also colour plate.

and the brain injured person attempting to orient the others to their reality (Yeates *et al.*, 2007). It is often the case that clients seem to shift between these two positions.

How do we begin to address such discrepancies? The cyclical process represented over the middle of the 'Y' represents a process of guided learning that is influenced by cognitive models (e.g. Teasdale and Barnard, 1993; Conway, 2005), the use of behavioural experiments in cognitive behaviour therapy (CBT) (e.g. Bennett-Levy *et al.*, 2004), and Vygotsky's (1960/1978) ideas about learning and development. This thinking is present in the approaches described by Ylvisaker and Feeney (2000) and McGrath and King (2004). Here we elaborate upon these ideas and place them into a framework, comparable to the model of Ben-Yishay (1978) that describes a hierarchy of tasks required in rehabilitation, along with a model of ego-identity development. Common to these different approaches is the notion that learning and development should proceed in a 'dialectical spiral' or interplay between experience and cognition. Both CBT approaches and Vygotsky's writing emphasize collaboration. Vygotsky specifically notes the necessity to be working within the 'zone of proximal development', providing support to achieve goals that are difficult enough to aid development without being too difficult. Teasdale and Barnard's (1993) Interacting Cognitive Subsystems model highlights how enduring change in psychological therapy needs to occur at the implicational, rather than

propositional, level of representation. The implicational subsystem in this model is said to be involved in the representation of experiences and the development of sense of self. The propositional level of meaning deals with cold facts and information, and this does not necessarily have the capacity to drive behaviour in the way the implicational representations do. This explains how someone might 'know' something (e.g. going to the gym more often would be good for my health), but be unable to carry out the behaviour. Conway's (2005) self-memory system model highlights how autobiographical memory provides information based on past experiences. This is drawn upon in the present to form a 'working self', a representation that simultaneously links past experience to current sense-making and goal selection. Together these ideas indicate that supported, collaborative work to make new links between activity, experience, meaning and identity may help reduce discrepancy and support learning both internally and in relationships.

By establishing a safe 'therapeutic milieu' in which clients feel understood and supported by staff and peers, and where goals are set at the right level, preferably by (or at least with) clients, it is hypothesized that the arousal associated with the threat reaction can be reduced, and clients can begin to think differently about their situation. Developing a psychological formulation, a shared understanding, and applying the principles of behavioural experiments (Bennett-Levy *et al.*, 2004) allows us as a team, along with the client and others, to think about the predictions clients may make about their abilities, themselves and others and set out to systematically and safely explore these. The broad steps that link to form a repeating cycle are: making predictions, setting up experiments or tasks to test or explore predictions, observing the task and feeding back, and reflecting on the outcomes in relation to initial predictions, this then leading back to making new predictions and so on. Different team members may be involved in each of these steps, depending on the skills required. Once an activity has been completed, reflections might be made on 'what this says about my abilities and skills', 'what this says about the usefulness of this strategy' or 'what this says about me'. This approach has been advocated specifically in the practice of CBT following acquired brain injury (McGrath and King, 2004) and in adjustment to health problems and disability (Silver *et al.*, 2004). Early in rehabilitation, experiments may involve provision of, and reflection on, information about brain injury, to develop engagement in the rehabilitation process ('malleability' in Ben-Yishay's terms). Later experiments may involve role-plays, testing strategy use, or other activities that facilitate re-evaluation of a client's beliefs and expectations whilst also building skills.

As the 'discrepant' sides of the top of the 'Y' come together, clients begin to integrate the new reality of life post-injury with pre-injury representations of themselves, others and the world. This is often not done lightly and many clients express distress or an increase in low mood. However, whilst difficult to work with, if understood and anticipated this can feel less distressing for them. The possibility of grieving for losses and changes may begin, strategies may become more appealing to the clients as tools to help them move towards their goals, and unhelpful processes of avoidance or conflict in interactions with others can begin to shift. From this point, each client establishes a foundation that allows him/her to live life with a sense of 'safe uncertainty' (Mason, 1993), taking risks and failing at times, as we all do, and learning this is okay. Clients and relatives often report a sense of 'the old self coming back' to some extent, at this point. In our experience, it seems that the client may develop this sense as a result of intensive work in one or two specific functional domains, and learn this as a new 'truth' or 'possibility' about themselves. However, further support to generalize to other domains of social participation is typically warranted.

Once the client begins to achieve a more 'integrated' sense of identity, specific interventions can be used to develop a 'positive formulation' or 'identity map' (Ylvisaker and Feeney, 2000) to support maintenance of gains and change. By developing such an explicit positive formulation based on the experiences of the client, we aim to provide a concrete means of sharing an understanding with the client and significant others in the wider community. This can provide the template or blueprint for maintaining gains and managing setbacks. Further experiments can be set to develop and consolidate new or alternative beliefs, expectations or assumptions (Mooney and Padesky, 2000). Often clients are supported to identify a metaphor for the journey or struggle that encapsulates the key messages personal to them and their developing sense of identity. Such metaphors can prove to be powerful clinical tools. These principles are well demonstrated in later chapters in this book describing our work with Yusuf (Chapter 16) and his 'rules for business and life', and with Judith's (Chapter 17) 'U-turn approach' to life post-injury.

From change process to goal planning and social outcomes: the six core components of rehabilitation

In 1999, Prigatano wrote '... holistic neuropsychological rehabilitation consists of five interrelated activities: establishing a therapeutic milieu or community, cognitive rehabilitation or retraining, psychotherapy, the ongoing involvement and education of family members, and a protected work trial' (Prigatano, 1999, p. 178–9). In the process of reviewing recent research and emerging models of social interaction, cognition and emotion, to cast new light on the established holistic rehabilitation literature, the team has worked together reflecting on 'ingredients to Neuropsychological Rehabilitation' most recently reviewed by Prigatano in 2008 (pp. 985–6). We wanted to articulate for ourselves how our interdisciplinary team has been working since the Centre opened in 1996. There are some differences from Prigatano (2008) that perhaps reflect how our programme has evolved in the UK context. However we have used six similar headings to describe core components to the Oliver Zangwill holistic programme. These components, we suggest, are each central to the change process for the clients here given their complex, interacting social, emotional and functional restrictions. The six core components are described under the headings 'meaningful functional activity', 'psychological therapies', 'working with families', 'therapeutic milieu', 'learning strategies and developing skills' and 'shared understanding'. These core components aim to provide a link between specific documents for guiding practice by articulating more concretely the notions represented in the mission of the rehabilitation programme here, and the Y-shaped model of rehabilitation described above. Our thinking behind these core components is described below.

The therapeutic milieu

The 'therapeutic milieu' in holistic rehabilitation refers to the organization of the complete environment (physical, organizational and social aspects) so as to be of maximum support to the process of adjustment and increased social participation. A sense of safety, trust and cooperation is at the heart of the milieu in a holistic rehabilitation programme.

Fundamentally, we are all social creatures. Our cognitive, emotional and communication skills are of course relevant to activities in leisure and work, but beyond this our relationships with family, friends and work colleagues are most important to our mental health and well being. It is through these roles that we gain meaning in life and a sense of identity. Milieu-oriented rehabilitation recognizes that work to:

- improve awareness and understanding,
- reduce the impact of impairments on practical areas of the client's life, and
- facilitate changes in identity

necessarily occurs within a social context. The theory behind the milieu-oriented approach (Ben-Yishay, 2000) is that clients move from feeling isolated, with a disrupted sense of identity, to then feeling included and getting back in touch with themselves and others within the milieu. In the latter stages of rehabilitation and during follow-up, clients then build and extend this into their own social world. The social context can provide the 'meaning' to 'meaningful functional activity'.

People with brain injury may find it hard to organize themselves in unstructured environments. The milieu offers a structured and predictable timetable for each day to enable clients to engage in rehabilitation more fully. It is known from social psychology that often we are most likely to change our behaviour because of the influence of respected peers. So, in addition to the individual and group-based input of the clinicians, clients on the programme can help one another to change. Clients are expected to work together in some of their group activities. This contributes to both 'shared understanding' and shared responsibility towards one another. This is another important influence on the process of change as the clients learn their behaviour has a direct impact on their working relationships with others. Research also shows that the quality of our relationships with others affects our emotional, cognitive and behavioural functioning.

It could be argued that a series of individual interventions to address specific cognitive and emotional issues carried out in the client's community will achieve the same aims as 'milieu-oriented' rehabilitation. Such approaches may well be appropriate for some clients. However, a recent thorough review also notes research showing positive outcomes for holistic rehabilitation in terms of increased social and work activity. This approach is advocated for people with moderate to severe acquired brain injury (ABI) at least one year post-injury (Cicerone, *et al.*, 2005; Sarajuuri *et al.*, 2005). In addition, our experience and outcome data suggest this holistic approach is especially suited to people with mild to moderate ABI, who may also experience complex, interacting difficulties.

The core component of the programme relating to the development of 'shared understanding' is a key aspect to the development of the milieu. As clients begin to feel understood, not just in medical or psychological terms, but personally, this begins to foster a safe and supportive atmosphere. Physical organization of the programme is also important, for example ensuring all clients and staff have routine timetables of rehabilitation activity, that the environment is self-contained and not too challenging to negotiate, and that there are routine meetings which aim to involve all participants (clients, staff and visitors) in the day-to-day running of the Centre. A number of processes are used to facilitate this, echoing the recommendations of Ben-Yishay (1978, 2000), Prigatano (2000) and Christensen and Teasdale (1995). There is a very strong emphasis on collaborative working, and in addition to practical goal planning sessions; the staff team meet regularly to reflect on the emotional impact of the work and ways in which the team and client groups are contributing to the development of a safe milieu.

Shared understanding

The notion of shared understanding comes from the use of 'formulation' in clinical practice (Butler, 1998). A formulation is seen as a map or guide to intervention that combines a model

derived from established theories and best evidence with the client and family's own personal views, experiences and stories. At the OZC we apply this concept to all our individual clinical work, and to how the rehabilitation experience is organized as a whole. We expand this concept to include team philosophy, including shared team vision, explicit values and goals. Understanding of research and theory, sharing our knowledge and experience with other professionals and families, peer audit of the service, and the views and contributions of past clients are additional aspects of the shared understanding we seek to promote.

'Rehabilitation is now seen as a partnership between people with brain injury, their families/carers and health service staff' (Wilson, 2003, p. 294). Such a partnership relies upon a shared understanding between the client, family and clinical team.

We view the development of a shared understanding within an interdisciplinary team as essential to effective teamwork. Teams work best when everyone has a shared understanding of the team's aims and rationale. It is recognized that a range of theories and approaches are required in rehabilitation of brain injury (Wilson, 2003). This requires involvement of a range of disciplines. The shared understanding provides a means of integrating relevant approaches and guiding intervention. Empowering clients and families to make informed choices also requires the development of a shared understanding. A working alliance is perceived as 'crucial for shifting the patient from being a dependent, convalescing person to being a more fully functioning, independent individual' (Prigatano *et al.*, 1986, p. 155). From this a new way of making sense of the complex challenges of brain injury arises that allows new solutions to emerge that are specific and meaningful to the client and family. When the client and family are collaborators in developing this understanding and solutions, it is anticipated that the changes they make will be longer lasting. The client and family may complete rehabilitation with a new way of seeing themselves or their situation that engenders hope, supports self-advocacy, and helps resolve altered feelings of identity. This understanding also extends to their peers on the programme, to foster the therapeutic milieu and sense of mutual understanding within the Centre. By listening to our service users, bringing research into clinical practice and thinking creatively we aim to develop and innovate practice in the field and extend our understanding to others.

A number of processes exist to develop and maintain a shared understanding and exchange of information:

1. Collaborative clinical formulation
2. Individual programme co-ordinator (IPC, or 'primary therapist') allocated to each client
3. Interdisciplinary teamworking, including regular clinical team meetings and shared documentation
4. A goal setting process that involves the client, his/her family (where appropriate) and the interdisciplinary team
5. User group to involve clients who have previously attended the Centre in decision-making, evaluation and contact with new service users
6. Family involvement
7. Research, education and professional development

Meaningful, functional, goal-directed activities

When referring to meaningful functional activity, we are referring to all day-to-day activities that form the basis for social participation. These can be categorized into

vocational, educational, recreational, social and independent living realms. It is through participation in these areas that we gain a sense of purpose and meaning to our lives. Although we may not think about this consciously in everyday life, our activity enables us to achieve certain aims or ambitions that are personally significant to us and thereby contributes to our sense of identity.

The primary aim of rehabilitation is to enable individuals to live as full a life as possible after their injury, facilitating a sense of hope for the future. It is essential that rehabilitation has a practical focus, targeting social and practical roles and activities that are important to the client, their family and society in general. Models have been developed which help us think about 'occupation' in its broadest sense, for example 'project oriented intervention' (Ylvisaker *et al.*, 1999). These provide ways for professionals to support individuals to achieve both practical independence and self-fulfilment.

Goal setting is a method of organizing and evaluating client-oriented clinical activity. It is known to be helpful for improving motivation and mood during rehabilitation, as it may be difficult for individuals to notice changes in their situation post-injury, thereby reducing frustration or distress through lack of progress (McGrath and Adams, 1999). Setting specific, measurable, practical goals allows explicit feedback regarding progress to be shared between the client, family/carers, other professionals and the rehabilitation team. Together with the shared understanding or use of formulation, and the Y-shaped model of rehabilitation, goal setting helps clarify who is responsible for doing what. For the service and the team, setting such goals allows us to evaluate how effective the programme has been in helping clients achieve their goals. There is also evidence that involving clients in setting their own goals helps with maintaining gains after rehabilitation (Bergquist and Jacket, 1993; Webb and Glueckauf, 1994).

Setting collaborative goals involves working together with clients and their significant others to develop a 'shared understanding' of difficulties and resources. At the same time, the roles, values, skills, behaviours and environments that are important to them in the realms of independent living skills, work, study, social life and leisure are identified.

We recognize that our day-to-day activities and roles are complex and are affected by practical skills, the people around us, and our own feelings about ourselves, others and the world. In this sense, all aspects of the rehabilitation programme are relevant to enabling clients to make changes in these practical areas of their lives. Key techniques used in this process are: goal setting, formulation, activity analysis, reflection, problem solving and behavioural experiments (McGrath and King, 2004). The ultimate aim is that clients will develop more effective coping skills related to specific goals, and prepare for further application and generalization of these skills, with hope for the future replacing the sense of being overwhelmed by life after their injury.

These techniques are carried out both in one-to-one and group settings in the Centre, the local community and the clients' own homes. As clients come to the end of their programme, there is increasingly close liaison with professionals who will continue to support clients and their families, for example case managers, community teams, disability employment advisors and support workers. This helps to ensure maintenance of gains and generalization to new goal areas as the individual's life changes and moves on.

Learning compensatory strategies and retraining skills

All clients who attend the OZC rehabilitation programme have some kind of ongoing difficulties as identified through interdisciplinary assessment. Areas include cognition

and communication (e.g. memory, language, attention, problem solving, perception), psychological coping (e.g. emotion regulation) and physical (e.g. fatigue, fitness, stamina) domains. Problems in these areas affect their ability to participate in 'meaningful functional activities' in an efficient and effective manner. Research evidence (Cicerone *et al.*, 2005) and clinical experience suggests that the most effective way to address such long-term difficulties is through the application of strategies that compensate for the impaired function, although some specific areas of functioning may be amenable to retraining. Retraining is helpful for specific impairments, including communication, attention, spatial inattention and reading (Cicerone *et al.*, 2005) and improving physical fitness. The aim of rehabilitation is to enable clients to participate in their desired roles and activities, as identified through long-term goals. Compensatory strategies and retraining of skills is undertaken through participation in experiments or projects relating to clients' goals, with the assumption that many strategies and skills can be applied to other activities post-programme.

Compensatory strategies are alternative ways to enable individuals to achieve a desired objective when an underlying function of the brain is not operating effectively and can take a number of forms. These include:

1. cognitive compensation (e.g. using visual imagery to compensate for verbal memory difficulties; using a mental routine for managing impulsivity or anger, and clarification to ensure effective communication);
2. enhanced learning – techniques such as errorless learning or spaced retrieval that lead to more effective learning of new knowledge or skills;
3. external aids (e.g. using a diary for managing memory problems; checklists to remember exercise routines; alarms to increase attention to tasks; cue cards for keeping on track during conversation);
4. environmental adaptation – modifying relevant environments in order to reduce cognitive demands (e.g. working in a quiet, non-distracting room to aid concentration; holding important conversations when less fatigued).

Retraining is undertaken to improve performance of a specific function of the brain or skill, and to improve performance on a particular task or activity. Retraining also helps to address skills lost through lack of use, for example, through not being at work since an injury, or physical deconditioning.

The process of learning strategies for managing impairments and building skills begins with clients being supported to develop a good awareness and understanding of the nature of their difficulties. This is achieved through group work (e.g. Understanding Brain Injury (UBI), Strategy Application or Project Groups, Independent Living, Cognitive, Communication, and Mood Groups) and individual sessions with team members. Through setting up experiments and projects, gaining objective feedback and reflecting on the experience via the 'Y-shaped' process described above, clients are encouraged to develop awareness of their skills and situations so as to be as effective as possible. Clients are encouraged to identify opportunities to discover and learn strategies to participate in activities, initially within the Centre, and then at home or community settings. Such work ties in with 'psychological interventions' by providing experiences on which to reflect and learn from, and ultimately feeds into 'meaningful functional activity', thus also contributing to social participation and improved sense of identity.

Psychological interventions

Psychological interventions are based upon specific psychological models, which in turn are used to guide formulation-based work to address the specific needs of the individual or family. Approaches from these models provide ways team members can engage the client in positive change and tackling specific problems.

People with ABI may complain of difficulties managing their anger, be depressed or anxious, describe difficulties coming to terms with their injury and experience disruption to personal and social relationships. The distress associated with changes post-injury (or the 'catastrophic reaction') may be managed through the individual avoiding certain situations or challenges, or through changes in interactions with others. The literature and clinical experience inform us that many people with ABI experience a range of emotional and behavioural changes, which may change over time and which present challenges to their ability to engage in rehabilitation and achieve their optimum potential in their life roles and functioning. Feelings of threatened, altered or lost identity (Tyerman and Humphrey, 1984; Nochi, 1997, 1998), or being misunderstood or judged by others (Nochi, 1998) are common. Emotions, behaviour, identity and awareness following brain injury can be affected by the following six broad areas (Williams, 2003):

1. biological, organic and 'body process' factors, e.g. pain, fatigue, type and area of neurological damage, cognitive impairment;
2. pre-injury factors, e.g. previous lifestyle, identity, roles, goals, skills, coping, relationships;
3. coping styles, e.g. avoiding difficulties, or using alcohol;
4. adjustment to a changed situation, i.e. the injury and its consequences;
5. relationships with and the reactions of other people;
6. social contexts and environments (e.g. home or work, social situations, community) and availability of helpful information.

It is understood that the psychological consequences of brain injury are complex and interacting. These consequences often present challenges to the person in his/her day-to-day life, in rehabilitation, and to the people around them, including family and professionals. Within any comprehensive rehabilitation service these consequences should be understood and addressed by all members of the clinical team involved with that person. Good evidence exists for the use of cognitive, behavioural, family, and interpersonal therapies, educational and group approaches in addressing mental health issues in the general population. Evidence for psychological therapies after brain injury is limited, but there is some suggestion that holistic approaches and those integrating work on emotional adjustment and cognitive strategies and skills may be useful (Cicerone *et al.*, 2005; Tiersky *et al.*, 2005).

Detailed assessment and formulation provides a means of building an initial 'shared understanding' with the client, family, rehab team and others (see Figure 1.2, Chapter 1). By understanding who the person who had the injury is, his/her background, family and culture, and the problems arising as a result of the injury, the factors underlying problem areas are identified and addressed by different members of the interdisciplinary team. The aim is to engage with the client's 'phenomenological field' (Prigatano, 2000), and together reflect on the specific personal meanings associated with the injury. Psychological interventions are an integral part of the structure and organization of rehabilitation activity, in that they are dependent on, and feed into, experiments and projects undertaken by clients in functional domains.

By creating a 'therapeutic milieu' and offering opportunities for engaging in 'meaningful functional activities', we aim to provide a safe and supportive context for change. The process of change is understandably demanding at times and is supported through a range of psychological interventions:

1. Individual psychological therapy sessions between client and clinical psychologist.
2. Family consultation involving client, relatives and therapist(s).
3. Individual rehabilitation sessions that target processes that may present a vulnerability to psychological distress.
4. Neuropsychiatric consultation and intervention, e.g. medication.
5. Group sessions providing general information about the emotional consequences of brain injury and strategies for clients, carers and relatives.
6. Opportunities to share experiences with others who have experienced brain injury, in both group and informal situations.
7. Opportunities to engage in 'experimental' or project-based group and individual work for exploring new ways of responding to challenging situations, integrating learning across the programme.

Specific psychological approaches used include cognitive and behavioural psychotherapies and techniques, supportive and educational counselling, group psychotherapy, systemic approaches, motivational interviewing, personal construct psychology, and narrative and positive psychology models and therapies.

Working with families and carers

Families and carers sometimes report feeling like an 'afterthought' in rehabilitation. Recent policy in the United Kingdom (*National Service Framework for Long Term Conditions*: Department of Health, 2005) highlights how families and carers experience a significant burden following ABI, and recommends provision of support. A number of different kinds of support can be provided. We define our work with family and carers in terms of providing information, providing opportunities for peer support, involving family and carers in rehabilitation, and providing individual family consultation or therapy.

We explicitly recognize the 'ripple' effect of how brain injury impacts not just individuals but those around them. We also recognize that these effects vary from family to family, and over time. Research highlights how relatives and carers may experience confusion, strain, uncertainty, isolation and family tensions in response to changes in roles and financial status. The needs of child relatives are very important but often neglected. Carers may be family members, friends, volunteers or paid support workers. The overlapping and discrete needs of these groups are incorporated into our work because of the level of unmet need, and because families and carers form part of the important context which influences coping and adjustment post-injury.

There is evidence to suggest that working with relatives and carers may help support the client's individual rehabilitation. By developing a shared understanding not only with the client but also family and carers, they become part of the therapeutic milieu. This facilitates the transition from learning in the rehabilitation centre to developing skills and roles at home and within their local community, thereby increasing social participation.

There is a lack of research to support the effectiveness of specific interventions for working with families, despite the high level of need (Oddy and Herbert, 2003). Our involvement with family members occurs in the following ways:

1. Involving family and carers in assessment and rehabilitation.
2. Family members can have access to a copy of all reports (subject to the client's permission).
3. Family members are invited to attend the first induction day on the programme to find out more about what it entails and how they may be involved.
4. Family members and others providing support are invited to formal goal setting and review meetings following assessment and at key stages of the rehabilitation programme.
5. The IPC specifically liases with family members on average once a fortnight during the six-month rehabilitation programme.
6. Families may be invited to attend consultation sessions both in the Centre and in the home environment to facilitate the shared understanding.
7. Providing information: an 'understanding brain injury' educational day is run four times a year specifically aimed at non-professionals. There is also access to reference information, e.g. books, leaflets and videos, within the Centre.
8. Providing opportunities for peer support through an ongoing 'relatives' group'.
9. Providing individual family consultation or therapy.

These core components and some of the work mentioned is articulated further in Sections 2 (group work) and 3 (clinical cases). Here we continue with our description of the rehabilitation process, starting with assessment.

Assessment and rehabilitation procedures

Following referral (which is usually from a medical consultant, a psychologist, an occupational or speech therapist or a personal injury lawyer), clients come for a one-day preliminary assessment. Most clients are accompanied by a relative. Both client and relative are interviewed by two members of the team (together and separately), the client will undertake some standardized tests and both parties will complete some questionnaires. The client, relative and staff involved meet at the end of the day to discuss the findings and decide whether or not to proceed to the next stage, the detailed two-week assessment. We have to feel we can help the client with his/her problems and the client has to feel willing to attend and work towards some mutually agreed goals to be determined at a later stage.

The two-week detailed assessment includes further standardized tests, functional assessment, interviews and questionnaires together with attendance at some of the groups (to be described in Chapters 14 to 19) and consideration of possible goals. A member from each of the four main disciplines of clinical psychology, occupational therapy, speech and language therapy and physiotherapy is typically involved in the detailed assessment. Each discipline will administer their own assessments, observe how clients relate to other people in the Centre, see how they cope in groups and with set functional activities, and consider whether clients are likely to benefit from the full programme. The formal goal planning process commences during this time. The purpose of this system of setting goals and specifying how they are to be achieved is to provide a clear direction to each client's programme and to help everyone monitor the programme. Appropriate goals are identified through discussion with the client, relatives or significant others and staff members. Goals are extended or adjusted as necessary throughout

the programme but the initial, preliminary goals are negotiated at the end of the detailed assessment period.

Each client has his/her own IPC. Any permanent and professionally qualified member of the team can take on this role and we try to ensure that no more than two clients are allocated at any one time to any one member of staff. A second IPC is allocated to provide additional support or cover absence as required. Once clients have entered the programme, following the two-week assessment, they meet with their own personal IPC to ensure the programme is co-ordinated to meet individual needs. The IPC acts as a link person between the client and other team members, relatives, significant others and any agencies involved in the client's programme.

There is an early meeting to confirm and, if necessary, adjust the goals. These are monitored and reviewed weekly by the IPC and about fortnightly by the team. Clients are given copies of the goals set and the progress made to keep in their personal files. Reports are written following (1) the initial one-day assessment, (2) the two-week assessment, (3) the intensive part of the programme, (4) at the end of the programme and (5) the three-month, six-month and twelve-month reviews.

About 60% of our clients are funded by their own local health authority (i.e. the place of their permanent residence) and about 40% by personal injury lawyers. The only people who are self-funded are, as a rule, those from overseas. Although we do not encourage overseas clients because of the difficulties in ensuring that the integration phase goes smoothly, there are times when acceptance is the lesser of two evils so we do occasionally have people from other countries especially if a family member can accompany them or they have relatives in the United Kingdom. For those people who are not considered suitable after the preliminary or detailed assessments, we offer advice on where to go next.

The client's day begins at 10 a.m. and finishes at 4 p.m. Punctuality is an expectation for both staff and clients (for whom it may also be a rehabilitation goal), and everyone has an individual weekly timetable that is reviewed each week. An example of a typical client timetable can be seen in Table 4.1.

Because the programme is non-residential, some clients travel in by car, bus or train each day. Transport is provided to and from the station. For others living further afield we help with accommodation in local bed-and-breakfasts or small hotels (this is seen as part of their rehabilitation). Occasionally a physically dependent or amnesic client will reside elsewhere in the hospital or a family member will rent a flat and move in for a few months. At times, a support worker may be arranged to provide specific support to clients in the hours when the programme is not running. Typically such support is social or emotional in nature but also extends to practical difficulties, for example with preparing meals or orientation to the local area. Most clients who require accommodation during the week return home at weekends.

Content of the programme

Individual sessions

The daily individual sessions are planned according to each client's needs. Occupational therapy sessions may cover skills such as fatigue management or development of memory and planning systems, as well as leading areas of social participation such as setting up the work experience for the second phase. Similarly speech and language therapy sessions

Table 4.1 Example client timetable

Time	Monday	Tuesday	Wednesday	Thursday
10.00 to 10.20 a.m.	Community Meeting	Community Meeting	Community Meeting	Community Meeting
10.20 to 10.50 a.m.	IPC (Donna)	Life skills Group	Work goal (Donna)	Cognitive Group
10.50 to 11.20 a.m.	↓	↓	↓	↓
11.20 a.m.	**Coffee Common Rm**	**Coffee Common Rm**	**Coffee Common Rm**	**Coffee Common Rm**
11.40 to 12.10 a.m.	Psychological Support Group	↓	Cognitive Rehabilitation (Fergus)	Psychological therapy (Siobhan)
12.10 to 12.40 p.m.	↓	↓	↓	↓
12.40 p.m.	**LUNCH**	**LUNCH**	**LUNCH**	**LUNCH**
1.40 to 2.10 p.m.	Cognitive Group	Individual Communication Work (Leyla)	Mood Management Group	Independent Session
2.10 to 2.40 p.m.	↓	↓	↓	↓
2.40 p.m.	**TEA**	**TEA**	**TEA**	**TEA**
3.00 to 3.30 p.m.	UBI Group	Strategy Application Group	Independent living skills goal (Jacqui)	Weekly Review
3.30 to 4.00 p.m.	↓	↓	↓	↓

may address underlying difficulties with expressive, receptive or social communication, or take a lead in functional domains such as social leisure activity. Physiotherapy sessions are usually focused on setting up exercise regimes and as far as possible clients are supported to access community resources to work on physical areas. Clinical psychology sessions cover both cognitive rehabilitation and psychological therapy. Where interventions are protocol based, rehabilitation assistants may carry out the rehabilitation activity. There is some overlap between professions in what is offered, although the psychologists have specific responsibility for supporting and developing formulation to guide team intervention and addressing emotional disorders. Sessions are linked through the experiments and projects described earlier in the chapter. Interdisciplinary working is achieved through the development and maintenance of the shared understanding, again described earlier.

Group sessions

As stated above all clients have both group and individual therapy. Most group sessions are run in a seminar format. The group leader usually has a handout and presents information on a whiteboard, flip-chart or PowerPoint slides. Clients take notes, ask questions, share experiences relating to the topic and offer explanations to each other. Information is mixed with exercises to help practise skills, develop awareness or test out predictions through small behavioural experiments. At the start of each week in the community meeting, the staff team provide a preview of the topics coming up in groups, and clients share out the note-taker role. Note-takers then facilitate the discussion at a meeting at the end of the week in which the main learning points and reflections from the week are identified and discussed. The note-taker may be asked to sum up at the end of a session and tell the group what were the main points of the previous session. All clients attend most of the groups. We may also change groups if we feel that we can improve on the existing state of affairs. For example we used to start the day with a Cognitive Strategy Group, the purpose of which was to help clients become aware of their cognitive problems such as memory, attention, speed of thinking and visual processing and to discover how these might affect functioning on a variety of written and verbal tasks. Clients were taught about various compensatory strategies relevant to their needs and they were given the opportunity to practise these strategies. They were also encouraged to relate the tasks carried out within the Cognitive Strategy Group to everyday activities. So, if someone had difficulty with a visual scanning task, he/she might be asked how this could affect him/her in the supermarket or kitchen. During the second year of operation, however, it was recognized that clients struggled to generalize learning from these sessions and so it was agreed to focus more on functional tasks. We identified that there was a need to more actively support clients to plan and organize themselves, so we then started the day with a Daily Diary Group whereby all clients would go through their plans for the day and ensure they had a system for remembering what to do and when to do it. Currently, we aim to apply the model of experiential learning across the programme, including groups. For example, we now include functional groups such as the 'Strategy Application Group', which provides the client group with projects that they work on together. This activity is used as a means of developing awareness and opportunities for testing out strategies. We place a greater emphasis on experiential learning within the cognitive and emotional groups, so information is presented, discussed, an

exercise carried out, and reflections made. Team members may draw upon group experiences with the client to facilitate individual psychotherapeutic, communication, cognitive or functional work.

Because we try to follow an interdisciplinary style of work and blur the boundaries between the different professions (while still making use of professional expertise) most of our groups can be run by any of the professional staff. The exceptions are the Psychological Support Group that is always run by two qualified clinical psychologists and the Communication Group that is always run by one of the speech and language therapists. In the past we have run an Independent Living Skills Group lead by one of the occupational therapists and a Physical Fitness Group run by the physiotherapist. All others can be run by any trained member of staff and we regularly rotate the group leaders. Both the principles of linking information, activity and meaning, as well as the specific content (skills and topics covered) are seen as essential to facilitating the 'Y-shaped' change process described above. The main groups run on the programme (described in Section 2 of this book) are:

- Community Meeting
- Weekly Review
- Understanding Brain Injury Group
- Cognitive Group 1 (Attention and Goal Management)
- Cognitive Group 2 (Memory)
- The Psychological Support Group
- Mood Management Group
- Strategy Application Group/Project Group
- Communication and Social Skills Group
- The Relatives and Carers Group
- User Group

Work experience

During the intensive part of the programme, clients are encouraged to think about their future plans after the current rehabilitation is completed. If return to paid employment is an option then a work experience opportunity may be arranged to take place during the integration phase of the programme. The best situation is when an employer is holding open a job, although this is rare in practice. In this case the occupational therapist (OT) liaises with the employer, identifies particular tasks and skills required for the job and how the consequences of the injury may impact on these areas, and works with the client and team on identifying compensatory strategies to optimize the client's work-related skills and behaviours. If no job is open to the client, a voluntary work experience is identified, if possible in an area of identified vocational interest. Once a specific work placement has been established, the OT will make contact with the placement provider, conduct a risk assessment and draw up a workplace agreement to clarify roles and expectations between the Centre, client and work experience provider. Evaluation forms are completed separately by the employer and the client and then compared and discussed with the team (see Chapter 12). The OT monitors the work experience through regular contact with the employer, and uses feedback to support the client to make a realistic vocational action plan for post-programme. Support agencies in the community are identified to enable this plan to be pursued.

Work experience can be used to assess a client's potential for paid employment and also give clients the opportunity to generalize the strategies learned during their group and individual sessions at the Centre. The work experience becomes a new context for the client to test out strategies and skills and to expend their experiential learning started within the Centre during the intensive phase, thus enabling continuity of the change process. Provision of good quality feedback is essential to this process. If necessary, the client can be shadowed by a member of staff to see what skills are required for the job, or the client can shadow a work colleague to see how things are done. Initially clients are likely to be engaged in the work experience while attending the Centre, say two days at the Centre and two days at the work placement. At the Centre clients have the opportunity to discuss any difficulties with the job and to practise any skills that need to be developed to make the experience more successful. Sometimes we may run a Work Skills Group prior to clients starting on a work placement (see Chapter 12).

Other activities at the Oliver Zangwill Centre

We usually have one overseas visitor at the Centre to learn about our approach. Our first visitor was a neurologist from Italy who stayed for a year. Most visitors stay for about three months and we have had therapists and students from Japan, Germany, Denmark, Thailand, China, Switzerland and Argentina, to name but a few. We are also heavily engaged in research. We have the opportunity both to apply the latest research findings and to develop new assessment and treatment procedures. One of our most successful series of studies was the work on NeuroPage described in Chapter 2. Other research projects include the investigation of new treatment techniques and strategies such as comparing different attention training strategies, long-term follow-up of our clients, a comparison of different types of memory aid, understanding and treating changes in emotion and sense of self, clinical assessment and management of social communication, and the development of new standardized assessment procedures.

Conclusion

There is no doubt that units like our centre are sorely needed throughout the world. Too few people surviving brain injury have the opportunity to experience this kind of rehabilitation. As Greenwood and McMillan (1993) said in a report commissioned by the Department of Health '. . . the absence of a specialist rehabilitation service for victims of brain injury has been the norm' (p. 250). They went on to say that this situation is 'woefully inadequate' despite the fact that there is mounting evidence of the clinical and economic effectiveness of rehabilitation as we pointed out in Chapter 2. A review of recovery of cognitive functioning following non-progressive brain injury (Wilson, 1998) suggested that rehabilitation could improve cognitive functioning (Ponsford, 1995; Merzenich *et al.*, 1996; Tallal *et al.*, 1996; Katz and Wertz, 1997; Robertson, 1999; Wilson, 1999). Rehabilitation programmes may work through helping people to compensate for their difficulties (Wilson and Watson, 1996) or through achieving restoration or partial restoration of functioning through plasticity and exercise. Robertson (1999) suggests that restoration may be possible after small lesions while compensatory processes are more likely to underlie recovery from larger lesions. Kolb (1995) believes language skills show a greater propensity for recovery than other cognitive functions. Attention deficits may also respond to specific training in certain circumstances (Sturm *et al.*, 1997), particularly with regard to unilateral neglect

(Robertson *et al*., 1995). However, to meet the needs of clients and families struggling with the multiple challenges of life following brain injury more than stand-alone cognitive rehabilitation is required. In this chapter we have described an evolution and adaptation of the established holistic or milieu-oriented approach consistent with the founding principles described by Yehdua Ben-Yishay. We have incorporated interventions from recent research and insights from a range of psychosocial theories to address complex interacting social, emotional, cognitive and functional needs, as well as organizational challenges. However, further research is required to investigate the interplay between cognitive and emotional changes, social context, and the process of change in rehabilitation. Furthermore, identification of the active ingredients of holistic intervention would perhaps help in the provision of more cost-effective and clinically effective, community-based programmes, as is being explored by our centre, and by others.

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Section 2
Chapter 5

Group interventions
The Understanding Brain Injury (UBI) Group

Barbara A. Wilson, Andrew Bateman and Jonathan J. Evans

Introduction

The Understanding Brain Injury (UBI) Group, it could be argued, is the most important group of the programme at the Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation. It is, perhaps, the main way of helping clients understand what has happened to them, how they have been affected by their brain injuries and what kind of recovery to expect. This information forms the basis of increasing awareness and self-esteem, and significantly contributes to the process of developing both a 'shared understanding' and a safe 'therapeutic milieu' as described in Chapter 4. Although the consequences of brain injury (e.g. memory, attention and emotional problems) are covered in more detail in other groups, without the knowledge and acceptance that we try to instil in the UBI Group, the other groups are thought to be less likely to succeed.

Central to the philosophy of the Centre is giving clients, where possible, the opportunity to develop good awareness of their strengths and weaknesses, and learn to self-advocate. Brain injury can be a bewildering experience, particularly in the context of cognitive impairments that make it more difficult to notice, understand or respond to problems. For the vast majority of clients, knowledge of brain injury and its consequences is limited to the client's own prior experience of it. One of the aims of the UBI Group is to normalize the consequences of brain injury; the educational, seminar-style format is used to describe how the brain works and how it may be affected by injury. Rather than confronting clients with the consequences of their own injury directly, the seminar format conveys a sense that there are many possible consequences of brain injury and the client has the opportunity to recognize and learn about those consequences that affect him/her. Discussion within the group is also used as means of clients modelling the process of discovery and awareness for others. This follows the cyclical process of learning of the 'Y-shaped model' described in Chapter 4, whereby in the early stages of rehabilitation clients are often engaged in exploring and reflecting on new information within a safe environment to begin to imagine new possibilities ('information' based behavioural experiments). Clients will often comment when they recognize a difficulty (e.g. attention difficulties) that they experience. Another purpose of the group is to explain, and demystify, some of the technical language associated with brain injury. Clients may have read reports about themselves, but not fully understood the content. They may not have had terminology explained to them previously. An aim of the group is therefore to enable clients, where

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possible, to become comfortable with the language associated with their brain injury. There continues to be stigma attached to being 'brain-damaged' or having cognitive impairments. A further aim of the group is to enable clients to understand the relationship between injury and impairments and the difficulties that they are experiencing.

Although clients often start to attend the UBI Group during their two-week detailed assessment in order to see what happens and to get a snapshot of the group, the syllabus actually starts when clients begin the full programme. All clients are required to attend the UBI Group. This group typically lasts for approximately eight weeks, with a one-hour session each week. However, depending on the learning styles and capabilities of the participants, we have also organized the delivery differently, for example including UBI Group meetings four times a week for half an hour each session. The structure depends to some extent on the clients' needs and speed of working but in either case the group can run throughout the 12-week intensive phase if necessary. The group is usually comprised of four to six clients and two members of staff from different disciplines. The group work is backed up in individual sessions during which clients start to build up their own personal portfolio. A suggested template for this portfolio is presented in Appendix 5.1.

At the start of each session the group leader welcomes everyone to the group and asks someone to summarize what was said last time. The information for each session is often presented using a computer projector. Discussion and questions are encouraged at all times, particularly when something presented relates to the client's own experience. In addition to the slides, there is always a model brain in the group and other audio-visual support, such as video-taped examples, and group exercises are used when appropriate. Sometimes the session ends with a quiz to try to reinforce the information learned. The material from the session is given to each client as a handout to put in their own folders.

Syllabus

There are three main parts to the syllabus: neuroanatomy, mechanisms of injury and mechanisms of recovery. Thus perhaps two sessions would be spent on neuroanatomy, three sessions on mechanisms of injury and three on mechanisms of recovery. We invite the participants to request topics of personal interest, meaning that some cohorts have asked for extra information about a range of topics, for example recent groups have asked for sessions to cover 'head injury and risk of dementia', 'altered sleep and dreams' and 'sound perception and noise sensitivity'.

We now present some examples of the individual session plans for this group although we wish to reiterate that we are always prepared to be flexible, increase or reduce the number of sessions if necessary, work at the best speed for individual clients and add or adapt the material as required.

Session 1: building motivation to learn

The handout for this session is included in Appendix 5.1. This session is designed to build motivation to take part in the group and clarify learning outcomes. Participants are invited to discuss reasons for wanting to learn about brain injury. We spend some time using a questionnaire to identify priorities and state some learning outcomes for the group. The aim of the homework following this session is to identify topics not listed in the pre-prepared syllabus. ('Please take some time to reflect on the session and finish the statement "The thing I want to find out about my brain injury is . . .?" ').

Sessions 2 and 3: neuroanatomy

Clients are welcomed to the group, homework from the last session is discussed and then main aims of the session are outlined. These are first to introduce the anatomy of the brain and to familiarize people with the terminology used. Second, clients will learn how the brain can be damaged through different types of injury and illness (for example traumatic head injury, stroke and encephalitis). The third aim is to develop an understanding of the mechanisms of recovery from brain injury and the fourth aim is to learn about the consequences of damage to different areas of the brain. Once any questions and discussion points have been raised, a diagram of the anatomy of the brain and skull is shown. The leader uses this to describe the position and the functions of the cranium, the cerebral cortex, the cerebellum, the brain stem, the spinal cord and the cerebrospinal fluid. This is backed up by reference to the models of the brain that are always present (there are a helpful range of high quality models available from Adam,Rouilly (www.adam-rouilly.co.uk/)). Questions and answers are encouraged throughout, it is worth repeating here that clients are provided with all information on handouts and are also encouraged to take notes. There are some very good web-based resources available to support education of anatomy. For example, *The Whole Brain Atlas* (Johnson and Becker, 1995–1999) provides simultaneous trans-axial, sagittal and coronal magnetic resonance images with clear arrows that aid identification of individual features. We have also found it helpful to use images available from recent medical journals. For example, Nakayama *et al.* (2006) used diffusion tensor magnetic resonance imaging to examine individuals with closed traumatic head injury. We have found their article and images useful to enable clients to understand more about white matter tracts and the point is made that sometimes their routine CT scans did not show up significant changes that may only be visible using new imaging techniques. (A PowerPoint slide of the images used in the article is available from the Journal's website (http://jnnp.bmj.com/).)

In recent years, the clients have been able to obtain from their referring hospital a copy of their brain scan images on a CD-ROM. Usually in an individual session we look at the images and the neuroradiologist's report. We print out a selected picture and label it with the key features. This leads to further opportunity to explore the relationship between regions of the brain that may be injured and current understanding of their functions. This approach has found some research support recently in a small study by Roberts *et al.* (2006) that demonstrated improved awareness and reduced anxiety and depression after a similar short intervention.

Summary sheet to enable spaced retrieval of information

At the community meeting at the beginning of each week one client volunteers to feed back to the group. Encoding and retrieval of information is supported by the provision of 'summary sheets' for all groups, and these can be explicitly used for feedback at weekly review. The summary sheets are used at the end of each session. The group are encouraged to assist the volunteer to decide what will be the main points to be recalled at weekly review.

Sessions 4 and 5: mechanisms of injury

This section begins with a discussion of five types of brain injury, these being the most likely kinds encountered by clients seen at the Centre. These are: (1) traumatic head injury, (2) vascular incidents (stroke including subarachnoid haemorrhage and ruptured

aneurysms), (3) infections (usually encephalitis), (4) hypoxia (brain damage due to shortage of oxygen to the brain) and (5) brain tumours.

There is more time allocated to the understanding of traumatic head injury, however, as some 70% of our clients have sustained such an injury.

The group learns about the frequency of mild, moderate and severe head injury and further statistics are provided as required. Members also learn about the classification of head injury into open and closed head injuries. A diagram of the areas of the brain most often damaged after a closed head injury is shown and clients are encouraged to talk about their understanding of their own injuries.

Session 6: severity of injury and the intensive care experience

The next session focuses on the different ways of classifying the severity of injury. The two most common ways of categorizing severity are presented: we outline the way clinicians measure depth and duration of coma and the length of post-traumatic amnesia (PTA). We have found that some clients are keen to review their intensive care notes, to understand what happened to them. Occasionally if a diary has been kept by relatives or nurses at the bedside for the duration of this period, it has been possible in individual project work to tally the fragments of memory that an individual has for this period with the records. We certainly would like to encourage our colleagues in the acute sector to facilitate the keeping of this type of diary.

The group considers the pathology and physiology of traumatic head injury. The aim of this is to contribute toward making sense of the investigations and interventions that have been documented. For some individuals, the level of detail required has included reviewing drug charts and identifying when and where and by whom various decisions about their care were made.

Other types of insults to the brain are discussed. Feedback from clients has indicated that by learning about other types of brain damage, as they have become relatively expert in their knowledge they have valued being able to communicate with other individuals they meet in the Centre or at Headway, with an understanding of their peers' problems too.

Sessions 7 and 8: mechanisms of recovery

The final sessions of the UBI Group are concerned with mechanisms of recovery. This is considered under headings such as (1) neurological recovery, (2) coma, (3) emerging from coma, (4) emerging from PTA, (5) severity of injury and recovery duration, (6) developing awareness and changing, (7) managing awareness and (8) moving on. Resources illustrating these themes, including current scientific studies have been found to be helpful.

Session 9: 'How have others understood their brain injury?'

This session is used to start the process of clients deciding on work they may wish to undertake independently and that might be achieved over the coming months. Some clients have found it helpful to watch a film about another's experience of brain injury. One such film was screened on BBC Four in August 2004 (entitled 'Storyville: Who am I now?'; David, 2003) and is an exploration of post-injury changes by a well-known (in the UK) BBC journalist, Sheena McDonald, who suffered a traumatic brain injury. She challenges received wisdom that 'she must be different' and demonstrates, through interviews with her family members and clinicians who cared for her earlier in her recovery, her understanding of the

impact her brain injury had on her and those around her. Some of our clients have understandably found this a difficult film to watch and it has evoked a wide range of emotional reactions (e.g. anger, sympathy, frustration, gratitude). However, on balance, we have felt this to be a helpful exercise for a wide number of reasons including engaging clients about how they would like to communicate about themselves in the future. Consideration of the nature of the 'behavioural experiment' being carried out by presentating the film through liaison with the clinical psychologist carrying out psychological therapy, can help anticipate and prepare the client for viewing the film with a specific point of learning in mind. Time is required after watching the film to give chance to debrief with clients due to the nature of their reactions to this film, and this may be followed up individually in psychological therapy or other relevant sessions if used as a behavioural experiment.

Whilst development of the 'shared understanding' with some clients may be derived from working on factual information about the injury, or creating a timeline of events, for others this may be too complex or inappropriate given their goals. Development of metaphorical representations as a means of simplifying and conveying complex information has been advocated in standard cognitive therapy formulation, and has also been used spontaneously by many of our clients in their own sense-making post-injury. We have collected examples of artwork projects from previous clients who have chosen to do work like this that has differed from our basic portfolio. Some time set aside to look at these has been of inspiration to many clients. For example one client, Richard, used the letters of his name to create a mixed-media installation, a montage of photographs from different stages of his life, prior, during and since his hospitalization due to a subarachnoid haemorrhage (see Figure 5.1 for an extract from this).

The cover of this book presents another example of a client's artwork. Stuart experienced significant memory and planning problems. Associated with these were both cognitive and motivational barriers to thinking about the future as someone with cognitive disability. Initially he had thought about three sections to his UBI project detailing a description of himself before, during and after the illness that led to his brain injury. However, in the context of work taking place in psychological therapy, this was seen as potentially allowing maintenance of 'self-discrepancy' and avoidance of threat associated with thinking about the future in an accurate, realistic and helpful way. This was reflected on with Stuart and so his UBI project emerged as an experiment for thinking about past and future self in one go (as we believe is required to facilitate emotional adjustment). Stuart had previously thought of describing his pre- and post-injury selves as trees, and so it was agreed to try using a single tree as a means of representing himself. As with any behavioural experiment this was entered into tentatively with a sense of curiosity and finding out, rather than prescriptively. Stuart became quickly engaged in the project. He had been using 'mindmaps' (see Chapter 7, Memory Group) as a memory strategy for a study-related goal, and was able to build on this developing skill. He identified his roots as core, background facts about himself such as his senses, emotions and personality (confidence, determination, humour). His achievements are represented as fruits (his high school examination certificates) which he described as never rotting away, being 'always fresh', permanent achievements despite the brain injury. Some branches (without leaves) represent temporary losses, others depict where he recognized pruning (his injury) altered his capabilities although in many cases new shoots are emerging. Stuart was also able to talk about how different conditions affect growth and described what sunlight, rain and soil represented in his life. These ideas helped him discuss future use of support and strategies (in terms of people, skills, situations) which he had felt understandably ambivalent about. The

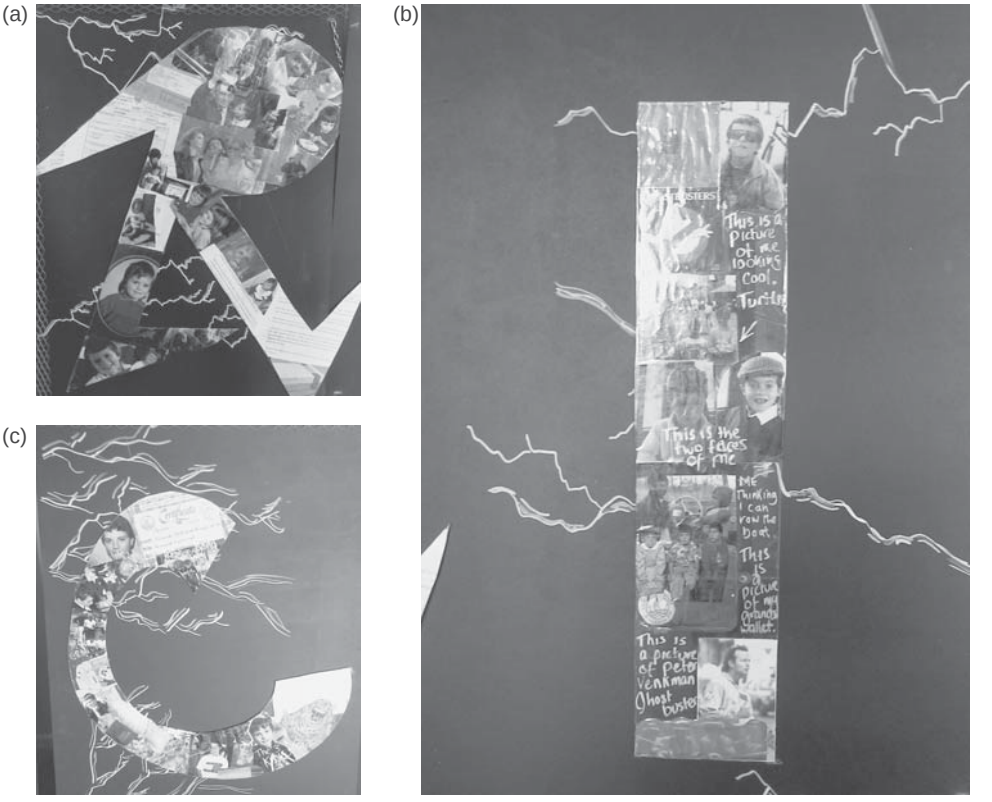
(a)
(b)
(c)
This is a picture of me looking cool.
This is the two faces of me
Me thinking I can row the boat.
This is a picture of my friends ballet.
This is a picture of Peter Venkman Ghost buster

Figure 5.1 Exploring 'Who am I?' through art: Richard created a timeline using the letters in his name to map out significant events in his life before and after his acquired brain injury. This figure shows an extract from his work, each letter stood approximately 1 m tall. Artwork by Richard Harrison, with permission.

UBI project as 'tree motif' therefore helped him to see that he has many life achievements that he can still feel proud of and that have not been lost due to the injury. At the same time, the notion of new and continued growth allowed him to use this metaphor to begin to have more helpful and concrete conversations about the future in other aspects of his programme.

Independent and supervised sessions

Portfolio or other individual creative work

As mentioned above, each client builds up his/her portfolio to explain what has happened to him/her and the consequences of the injury, illness or insult. The portfolio preparation and completion is done in individual and independent sessions and is a back-up to the UBI Group. We present in Appendix 5.1 some blank templates for various ways of completing the portfolio. There are four main sections, not all clients complete all four sections. When completed, clients, depending on their rehabilitation goals, present it to a family member, employer, colleague or member of staff to help others understand the effects of the brain injury. This is often one of the goals the client is expected to achieve as part of the rehabilitation programme (e.g. 'X will be able to explain accurately to his employer the nature

and consequences of his brain injury as rated by his individual programme co-ordinator). As the programme goes on and progresses into the community integration phase, the learning of information and integration of this information with developing skills, awareness and updated sense of identity becomes a central resource for the client, the team and for others as the client extends their shared understanding into existing and new contexts. This can take the form of a personalized 'toolbox' of strategies (see Yusuf, Chapter 16), metaphors such as Steven's tree, more detailed 'positive formulations' (see Judith, Chapter 17), or shared understanding and recommendations for support to make environmental and contextual changes (as in our work with Simon, Chapter 18, and Adam, Chapter 19).

Conclusions

This group touches on all other elements of the programme and provides the springboard for integrating knowledge with application of strategies in the participant's daily life as depicted in the 'junction' of the Y in the Y-shaped model. As a strand of the programme that is designed to build confidence in participants' knowledge about themselves and their condition it is consistent with the Department of Health (2006) backed 'Expert Patient Programme (EPP)' approach. At the present time the group differs from the EPP because it is not lay person- or patient-led, however, it is possible that wider participation in such a group could be enabled through training participants to facilitate future groups.

Systematic evaluation of the group in isolation using changes in scores recorded on the form suggested for use in session 1 (see Appendix 5.1), has not yet been attempted, and this is a target for future research. Preliminary inspection of these forms indicates that by week 12 of the programme, clients have routinely felt more confident about their knowledge. The important challenge is to establish if both reduced self-discrepancy or discrepancy with others, and improved performance in social participation-related goal areas is indeed dependent on participation in this group.

In conclusion this group emphasizes the need for an exploration of the details of an individual's brain injury as part of the theme of developing a shared understanding (Chapter 4). The materials we use for this group are also used for an Understanding Brain Injury Workshop for carers and relatives we run in the Centre four times a year (as part of our 'working with families and carers' core component, see Chapter 10). This is one route to extending the shared understanding beyond the Centre.

Appendix 5.1: Examples of handouts used in the UBI Group Session 1: building motivation to learn about brain injury

Understanding brain injury course

The aim of this document is to help summarize some of the options for this programme of learning.

Background

Understanding brain injury (UBI) refers to our approach to:

Sharing our knowledge (and lack of knowledge) about the brain and the impact of injury
Finding out about pathology (disease processes)

Finding out about cognitive consequences
Finding out about emotional consequences

It is the Oliver Zangwill Centre team opinion that sharing this information can help with adjustment and sense making.

Right at the start it is appropriate to be concerned about the risk of a negative focus – listing all the possible problems – or feeling overwhelmed by the potentially enormous syllabus.

However the general aims are about self-advocacy – (to be able to explain nature and consequences of BI), for clients to demonstrate understanding of nature of consequences through either spontaneous or prompted use of strategies in given situations, and in the rehab programme in general 'to understand who I am, my feelings about myself and discover new things'.

Methods of learning

Seminar presentations
Portfolio completion
Presentation to peers – poster or spoken
Artwork or video preparation
Creating a timeline
Finding metaphors from films or fiction
Guided reading
Previous assessment findings
Working with my brain scans

Understanding of Brain Injury Goals

Will vary from person to person….

Proposed syllabus

1. What is UBI? Overview.
2. Anatomy
3. Other general info, e.g. types of injury (open-closed injuries, etc.) severity of injury (PTA, GCS) (this may need to be spread over two sessions)
4. Watching the film 'Who am I now?'
   The next four weeks giving clients opportunities to talk specifically about their experiences, as well as providing information. Encouraging a compassionate understanding of yourself, cross-referencing to other groups.
5. Post-concussion syndrome
6. Subarachnoid haemorrhage.
7. Infection – Encephalitis
8. Summary, any other info that needs to be provided, reflection on what people have learnt, setting the agenda for individual projects.

Further options could include:
investigation into recovery processes,

fatigue, or other symptoms not planned to be covered in other groups;
myths and risks;
current research or future research;
physiology and biochemistry and drugs

… …

Learning outcomes

A range of possible outcomes from a UBI course are listed here

(a) Understanding brain injury demonstrated through change in behaviour and use of strategies
(b) Awareness of a range of possible strategies
(c) Ability to seek out and interpret information about brain injury
(d) Apply information to daily life.
(e) Hold multiple perspectives about the information

… … …

GOAL	HOW SATISFIED ARE YOU WITH CURRENT KNOWLEDGE?	HOW IMPORTANT IS IT TO YOU?
To learn about brain injury so that by 12 weeks…		
a) I can understand more about myself and why things go wrong		
b) I can feel more tolerant of myself		
ci) so that I will be able to explain to people in the Centre what happened		
cii) so that I will be able to explain things to my family		
d) so that I can explain to people who don't know me		
e) so that I will have some information I can refer to in the future		
f) so that I will know about where I find out more in the future		
g) so I can prepare a poster/ article/paragraph in my CV		
h) so I can understand my hospital notes		
i) to be aware of latest research		

GOAL	HOW SATISFIED ARE YOU WITH CURRENT KNOWLEDGE?	HOW IMPORTANT IS IT TO YOU?
j) to be able to advise researchers		
k) help others with brain injury		
l) contribute to the OZC website/book		
m) speak at a Headway meeting		
n) any other goals		

Templates for portfolio preparation e.g.

1a. The cognitive consequences of my brain injury

I have problems with (e.g. memory, attention, language)	This means that	A practical example of when this problem arose is

1b. The emotional/behavioural consequences of my brain injury

I have problems with (e.g. anger, anxiety, depression)	This means that	A practical example of when this problem arose is

1c. The physical consequences of my brain injury

I have problems with (e.g. restricted movement, pain, fatigue)	This means that	A practical example of when this problem arose is

2. Strategy tables: For my difficulties I am able to use a variety of strategies which may be used on their own or in conjunction with other strategies

I have problems with …. e.g. memory, attention (Note each difficulty separately)	Strategies I can use	A practical example of when I used these strategies for this problem is

3. Situation Specific Strategy Tables

Situation:

The cognitive/emotional/physical demands (e.g memory, irritability, fatigue, anxiety, planning)	These are the strategies that I used (e.g memory aid, mindfulness, mental checking, pacing)

4. Domain specified strategy tables

4a. The strategies I use to manage tasks and activities related to home/domestic life are:

The task, activity or area of need	The strategies I should be using

4b. The strategies I use to manage tasks and activities related to work/study are:

The task, activity or area of need	The strategies I should be using

4c. The strategies I use to manage tasks and activities related to my social life are:

The task, activity or area of need	The strategies I should be using

4d. The strategies I use to manage tasks and activities related to my leisure interests are:

The task, activity or area of need	The strategies I should be using

SESSION 9: how have others understood their brain injury?

UBI Group

The task is to watch a recording of the BBC film 'Who am I now?' with the following questions in mind:

1. How has Sheena gone about her Understanding Brain Injury?
2. Do you think she has succeeded?
3. What did she learn?
4. Which part of the film did you like best?
5. Which part of the film could you leave out?
6. Which part of the film was most about you?
7. What would you like to do for your UBI project – if the film gave you any ideas – or if you have some other ideas about how you can show that you have improved your understanding of brain injury?

Individual project work ideas

Understanding Brain Injury Portfolio: background information prompts

What happened to me and when did it happen?

What type of injury did I have (e.g. traumatic head injury, stroke, etc.)?

Which areas of my brain were damaged and how were they damaged (e.g. contusion to frontal lobes)?

What happened to me whilst I was in Hospital (e.g. operations, monitoring procedures)?

How long was I in hospital for?

What was my Glasgow Coma Score, Length of Coma, and Length of PTA (if relevant). What does this indicate?

What intervention have I had since my injury (e.g. in-patient rehabilitation, out-patient therapy, Headway)?

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Chapter 6

The Cognitive Group, Part 1: Attention and Goal Management

Jonathan J. Evans

Introduction

Memory, attention and executive deficits are the most common cognitive impairments in the clients who are referred to the Oliver Zangwill Centre for Neuropsychological Rehabilitation and they are therefore the focus of the Cognitive Group. The aim of this group is to help clients to develop a better awareness of their own difficulties in these areas, as well as gaining knowledge and experience of strategies that can be used to manage these cognitive problems. As with the Understanding Brain Injury (UBI) Group described in Chapter 5, the group format enables clients to learn from the group facilitators as well as from each other, through discussions of their own problems and strategies they have found helpful.

The group begins by focusing on attention and executive functioning (referred to using terms such as goal management or problem solving) and then goes on to look at memory. This chapter will describe Part 1 of the group, looking at attention and goal management (A&GM) together, as these concepts and the everyday difficulties associated with them overlap so much. We begin by considering the evidence addressing the efficacy of treatments for impairments in attention and executive functions.

Rehabilitation of attention and executive functions: the evidence base

The evidence base relating to the rehabilitation of attention and executive functions is relatively small. There is some evidence that training specific attentional functions using computerized cognitive training programmes might be beneficial (Sturm *et al.*, 2002), though there is less evidence as to whether such training programmes generalize to performance on functional activities. Evidence that training in the use of strategies to manage, or compensate for, attentional problems is beneficial is stronger (Cicerone *et al.* 2005). A meta-analysis by Park and Ingles (2001) suggested that there is good evidence to support the hypothesis that the performance of individuals with attentional impairments on functional activities can be improved through training. By working directly on functional activities, patients may develop strategies to compensate for attentional difficulties or in some cases become skilled at a particular task such that the task requires less conscious attention and is less subject to errors caused by poor attention. There is some evidence that sustained attention can be trained through gradual shaping on specific functional tasks (see

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Manly (2004) for a review). Within the A&GM Group the section on attention aims to help clients develop a better understanding of attention and better awareness of their own difficulties with attention and concentration, and then to learn how strategies for managing attention may be applied to everyday situations.

Several studies have reported success in improving aspects of executive functioning using a group-based skill retraining approach and we have drawn on this literature in designing the structure of the A&GM Group. For example, von Cramon *et al.* (1991) and von Cramon and Matthes-von Cramon (1992) described a group-based approach, which they termed problem-solving therapy (PST). They note that the aim of the treatment is to enable patients to be more effective in breaking down problems, adopting a slowed down, controlled and stepwise processing approach, in contrast to the more usual impulsive approach. The therapy explicitly draws on the problem-solving framework of D'Zurilla and Goldfried (1971) who used this approach in teaching adults with mental health problems to be more effective in mood management. The specific aim of the treatment group is to enhance patients' ability to perform each of the separate stages of problem solving. Tasks were designed to exercise skills in:

1. Identifying and analysing problems
2. Separating information relevant to a problem solution from unimportant and irrelevant data
3. Recognizing the relationship between different relevant items of information and if appropriate combining them
4. Producing ideas/solutions
5. Using different mental representations to solve a problem
6. Monitoring solution implementation and evaluation of solutions.

von Cramon *et al.* (1991) compared a group of patients who received PST, with a group of patients who received a control group-based memory therapy. They showed that patients who underwent PST showed some improvement in tests of general intelligence and problem solving compared with memory group control participants. von Cramon and colleagues demonstrated some generalization of problem-solving skills to untrained test tasks, though there was no evidence presented in relation to generalization to everyday situations.

Rath *et al.* (2003) compared outcome for 27 patients who undertook a problem-solving training with a control group of 19 patients who underwent what they described as 'conventional' treatment. The conventional treatment combined general cognitive remediation training and psychosocial work and involved 24 sessions, with 2–3 hours per week contact. The problem-solving group also involved 24 sessions, with one, 2-hour group per week. In the first 12 sessions, the focus was on what Rath *et al.* describe as 'problem orientation'. In this phase they addressed issues of affective reactions, attitude and motivation towards dealing with problems arising from the consequences of brain injury. The second 12-session block focused on the more specific problem-solving training, addressing the various stages of problem solving as in the von Cramon group described earlier. The impact of the group was measured with a range of neuropsychological tests, questionnaires and also a role-play of a problem-solving scenario that was rated by independent raters. Rath *et al.* found that the problem-solving training group improved (and the conventional group did not) on Wisconsin Card Sorting Test performance, on self-assessed ratings of problem-solving skills, clear thinking and emotional regulation, and perhaps most importantly on the observer ratings on the role-played scenario. Improvement was also maintained at a six-month follow-up.

So there is some positive evidence for the effectiveness of a group-based approach that focuses on each of the stages of the problem-solving process, encouraging participants to adopt a systematic approach to solving everyday problems.

We have also incorporated into the A&GM Group the concept of a mental blackboard as a metaphor for working memory, which is central to the process of problem solving or goal management. Levine *et al.* (2000) described the use of a goal management training (GMT) technique, devised by Robertson (1996). The GMT technique was derived from Duncan's (1986) concept of 'goal neglect'. The principle is that patients with frontal lobe damage fail to generate goal (or sub-goal) lists of how to solve problems (and achieve goals), and/or may fail to monitor progress towards achieving sub- or main goals. The mental blackboard is used to illustrate how tasks and subtasks are written in working memory, but which are also vulnerable to being rubbed off, leading to a failure to achieve intended goals. The training has several stages which are first defined for the patient: (1) Stop! Ask, 'What am I doing?' Check the mental blackboard, (2) Define the main task or goal to be achieved, (3) List the steps or stages needed to achieve the goal, (4) Learn the steps, (5) Carry out the steps, (6) Check – keep checking the mental blackboard and asking 'Am I doing what I planned to do?' Levine *et al.* (2000) provided some evidence for the efficacy of GMT in a group of people with traumatic brain injury and a single case study of a woman who had suffered herpes simplex encephalitis.

In the Oliver Zangwill Centre A&GM Group, we have combined the goal management and PST approaches.

Description of the group

The Cognitive Group runs during the first 12 weeks of the rehabilitation programme. The first half of the group covers attention and goal management and the second half memory. However the precise number of sessions allocated to each topic is flexible and will depend on the speed with which the clients progress in the group. The Cognitive Group meets once per week, for up to 2 hours with time allocated for breaks. The group is usually facilitated by a psychologist and an assistant psychologist. Each client has at least one additional individual 40-minute session each week to review materials from the group, develop understanding of how topics discussed in the group are of relevance to him/her and to identify how to apply strategies discussed in the group in everyday life.

The general outline of the attention and goal management section of the group content is provided below and is presented as six sessions, though as noted the material may be presented more quickly or more slowly, according to the needs of the particular clients. Most sessions will include (1) education/information and (2) a practical task to illustrate some aspect of attention or goal management and some sessions will also involve a 'homework' task set for completion prior to the following session. The education sections use a set of overheads, supported by discussion from the facilitator.

It is accepted that not all clients will have difficulties with all aspects of attention or goal management and hence some aspects of the group will be less relevant than others. Furthermore, there may be clients who are dealing well with some of their difficulties arising from attention or executive impairments. Here however the great benefit of the group is that these clients are able (hopefully) to endorse strategies being presented by the group facilitators.

The group programme begins by focusing on attention and then moves to discuss executive functioning, with a focus on the overlap between the two areas. As with all of the groups, there is a strong emphasis on facilitating discussion amongst the participating clients.

Session 1

Education

- Introduction and aims of the group
- What is attention?
  - What do people understand by the term attention?
  - Definitions of attention
- Functions of attention
  - Attention Sun – a visual illustration of the many cognitive functions that require attention
- What factors can disturb attention?
  - General factors that may affect attention
  - Ways in which brain injury may affect attention
- Examples of common problems with attention following brain injury
- Types of attention
  - Selective
  - Sustained attention.

The aim of the first week of the group is for clients to begin to understand more about attention, the fact that there are a variety of types of attention (which may be affected to differing degrees by brain injury), and how brain injury as well as more general factors (e.g. fatigue, environment, stress, pain) may affect attention. This information is designed to provide a background rationale for looking at ways of managing attention.

Practical Tasks

A number of practical tasks are undertaken to illustrate different types of attention. Examples include a computerized task of sustained attention, talking with someone while others are also talking (selective attention), sorting playing cards while holding a conversation (divided attention) and finding selected places on a map (selective attention).

Homework

The Attention Quiz (see Appendix 6.1) – participants are given a short questionnaire referring to various situations, asking them whether they feel that they have any difficulties in this situation and what type of attention is required, e.g.:

> Do you find it difficult to listen to one person talking to you, if you are in a noisy crowd of people? Yes/No
> What type of attention do you think this mostly involves?_____
>
> Do you find your mind wanders when you are watching a film or reading a book? Yes/No
> *What type of attention do you think this mostly involves?*_____

Introduction of self-monitoring diaries

As part of their individual work, clients are asked to complete a printed monitoring sheet which asks them to record examples of when they have noticed experiencing a problem with attention or problem solving/goal management. The aim of this is to begin to increase

clients' awareness of their attention/problem solving in everyday life and also identify situations in which some sort of strategy may be helpful.

Session 2

Review of homework

The group begins with a review of the Attention Quiz homework task. Usually this leads to further discussion of types of attention and the ways in which attention is more difficult after brain injury. This leads into the education section, which focuses briefly on the neuroanatomy of attention, again emphasizing how brain injury may lead to difficulties.

Education

- Anatomy of attention
- Linking brain injury to attentional problems
- Introduction to the concept of a mental blackboard
- Using the mental blackboard
  - Writing on the mental blackboard
  - Checking the mental blackboard.

The anatomy section presents some straightforward ideas illustrating that different parts of the brain have different functions in relation to attention. It is assumed that most clients will not remember all of the details, but hoped that this work reinforces the message that there are different types of attention, which may be affected differently by brain injury, and therefore a range of strategies may be required. The group is then introduced to the concept of a mental blackboard, derived from Robertson's (1996) GMT. This is a really useful concept, which is easy for clients to grasp and is used to make the link between attention and goal management. The mental blackboard is essentially an analogy for working memory, the mental workspace. Clients are introduced to how sustained attention can be thought of as keeping things on the mental blackboard, how selective attention is about putting one thing on the blackboard and keeping others off, how divided attention is about having more than one thing on the blackboard and switching between the two. The analogy extends to problems with attention – difficulties with selective attention mean that lots of things find their way on to the blackboard and it is difficult to focus on just one of them. Difficulties with sustained attention mean that something on the blackboard is rubbed off, usually being replaced by something else. The concept is also used to illustrate the way in which many situations require multiple tasks to be managed on the mental blackboard. One example used to illustrate this multitasking is preparing a meal. To further illustrate this, a practical task is undertaken, called the 'Chocolate Surprise Company' task.

Practical Task

Chocolate Surprise Company. This task takes about 20–30 minutes. The scenario is that the clients are all employees of a chocolate company. Each person is given an identity (Sales-person, Accountant, Personnel Manager) and a series of tasks (writing letters, compiling figures, making a phone call, checking suppliers' numbers) that need to be completed over the period of the exercise. Following the task there is discussion of how successful clients were in carrying out the tasks, links are made with the idea of a mental blackboard, and strategies spontaneously used (e.g. using a written plan) are highlighted.

Homework

Clients are asked to note and bring back to the group next week one example of where they have used their mental blackboard – this is explained as an example of multitasking, where they have carried out a task with several subtasks.

Session 3

Review of homework

The group begins with a discussion of the homework task. Clients are asked to describe an example of multitasking from the previous week. Typical examples include preparing a meal, going shopping, getting children ready for school and, for some, driving.

Education

- Introduction of strategies for managing attention
  - External environment
  - Internal environment
  - Fatigue/sleep management
  - Creating interest (e.g. PQRST see below).

This section of the programme presents ideas for managing difficulties with attention. It begins with focusing on the external environment, with the aim of encouraging clients to be better at managing potential distractions, such as noise distractions (TV, radio, people) and visual distractions (clutter, other things that need doing). Clients are encouraged to organize work/study and home environments to aid concentration. One aim is also to give clients the confidence to manage situations, being, where appropriate, more assertive than they may ordinarily have been. Clients are asked to give examples of where they have done this, to support each other. By way of an example, one client reported in the group that he had been for a medico-legal assessment and had asked for a noisy fan to be turned off as it was making it more difficult to concentrate. For this particular client having the confidence to make this request was a major achievement, and one that was made possible by having a better understanding of the relationship between his head injury, difficulties with concentration and knowledge of management strategies.

Strategies relating to the internal environment highlight the importance of mood and physical health (e.g. pain) in relation to attention and concentration. Links are made with work being undertaken in the Mood Management Group. One area of particular relevance here is sleep and fatigue management. Clients are taught the basic principles of good 'sleep hygiene'. Similarly, the principle of pacing as a fatigue management approach is emphasized. This links with the idea of allocating set times for tasks followed by a break and opportunity to review whether or not to return to the task immediately or later. There is discussion of the challenge of sustaining attention to tasks that are not interesting. This is illustrated with the practical task described below. Through this the principle of trying to manage level of interest in a task is introduced. One example of a method of doing this in one particular situation is the PQRST technique. This is essentially a memory strategy (Wilson, 1987), which can be applied in study situations (though we have also used it to help clients remember items of news from the newspaper to support general conversation). The acronym stands for Preview (skim read the text), Question (identify some questions to be answered when reading the text), Read (read the text), State (say the answers to the

questions) and Test (test memory for the text). One way of thinking about this task is that it represents a method of trying to increase the meaningfulness of the text to be read.

Practical task

Clients are shown two clips of video. One is tedious (we have used a clip of video of a tape recorder playing tones) and one is more interesting, or at least attention grabbing (e.g. a clip from a movie such as Star Wars). Clients are asked to comment on the experience of watching the two clips in terms of the demands on concentration and also the link with levels of arousal.

Homework

Clients are given two newspaper articles. One is considered dull (e.g. an article about government financial policy) and one more interesting (e.g. an article about a man recovering from a head injury). Clients are asked to read the articles and again reflect on how their ability to concentrate varies between the tasks, and how much they remember from each article.

Session 4

Review of homework

The dull vs. interesting article task is reviewed, leading to a further discussion of the importance of how meaningful a task is in relation to attention and concentration. There is further discussion of how to make tasks more meaningful, including use of techniques such as PQRST for very specific situations such as studying.

Education

- Training attention
  - Sustained attention
  - Divided attention
- Explaining attention problems to others.

The education section focuses firstly on a discussion of 'training' attention. The message given is that it may be possible to train the ability to sustain attention to tasks, but this is best done by training on the specific tasks of interest. For example if trying to improve the ability to read for longer, it is best to train on reading tasks, rather than for example training on computer games and hoping this will generalize to reading books. The central idea presented is that improved ability to concentrate (on a particular task) may be achieved by gradually extending the time on a task. One key concept here is about increasing awareness of attention so that time on a task is increased in part by being quicker to notice that attention has drifted so it can be returned to the task. Attention may drift just as often, but time on the task is improved by reducing the time off the task, by catching drifting attention quicker. We believe that much of the general education work in this group contributes to an increased level of awareness of attention, or, put another way, an improvement in metacognitive skills. These ideas are presented in the group, and are picked up in more detail in relation to each client in their individual sessions.

In relation to divided attention we again suggest focusing on specific task situations relevant in each client's life. The main strategy presented is to begin with one task, and increase skill level on this task before gradually introducing a second task. The idea is that

increasing skill level on one task reduces the attentional demands of that task, so allowing, in effect, a release of resources that are available to a second task, which can be gradually introduced. The case of David, described later in this chapter illustrates this principle very clearly.

A further section looks at how best to cope with other people's understanding of attention problems. This relates back to managing the external environment to some extent, through being assertive in relation to distractions. This sometimes necessitates an explanation to others, hence the importance of a good understanding of the relationship between brain injury, attention and strategies for managing attention. The practical task for this session is a role-play task in which clients practise explaining to others the nature of their problems with attention.

Practical task

Role-play in pairs, reversing roles. Each client is asked to explain the nature of their difficulties with attention/concentration. Feedback is provided by the other client in the pair and a facilitator who moves from pair to pair.

Session 5

Education

- Introduction to the concept of 'executive functioning'
- Anatomy of executive functioning – the frontal lobes
- Common problems after brain injury
- Introduction to the Goal Management (GM) framework
- When to use the framework
- Goal management step 1: identifying main goal.

The executive functions of the brain are introduced with reference to two metaphors, being similar in nature to those of the chief executive of a company or the conductor of an orchestra. Both can be said to have a directing, strategic or planning role, rather than being directly involved in the basic, routine tasks (of the company or the orchestra). Both are involved in monitoring activities, responsible for achieving the main goals of the company or orchestra and, when necessary, troubleshooting or problem solving. Through these analogies, the session focuses on ideas of goal management and problem solving. Discussion of the anatomy of executive functioning is limited to the point that the frontal lobes are important in this role and that the frontal lobes are very commonly disrupted by brain injury. There is then a discussion of the common forms of difficulty with executive functioning with an emphasis on (1) poor monitoring (framed in terms of not noticing a problem or not noticing that what I am doing is not going to help me achieve my goals) and (2) a lack of planning, leading to a difficulty initiating goal-directed behaviour (i.e. failing to do anything to solve problems) or a tendency towards being impulsive and 'acting without thinking'.

The GM framework was developed to provide clients with a structure to support problem solving. This is shown in Figure 6.1. Clients are also provided with copies of a blank template, which is used in the completion of several practical tasks over the coming sessions and is also applied to problems identified by the clients in their individual sessions. This is illustrated in Figure 6.2. The GM framework is provided on paper and for all of the subsequent group and individual sessions; it is referred to in order to help clients develop a good understanding of how it might be used. In a discussion of when it can be used, it is emphasized that the

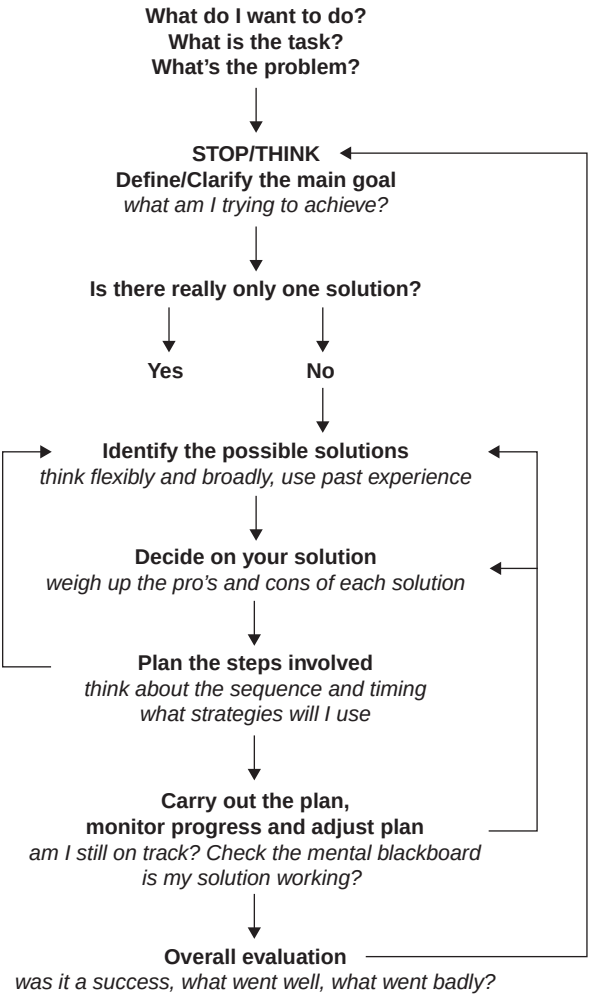
What do I want to do?
What is the task?
What's the problem?
STOP/THINK
Define/Clarify the main goal
what am I trying to achieve?
Is there really only one solution?
Yes
No
Identify the possible solutions
think flexibly and broadly, use past experience
Decide on your solution
weigh up the pro's and cons of each solution
Plan the steps involved
think about the sequence and timing
what strategies will I use
Carry out the plan,
monitor progress and adjust plan
am I still on track? Check the mental blackboard
is my solution working?
Overall evaluation
was it a success, what went well, what went badly?

Figure 6.1 The Goal Management (Problem Solving) framework (Evans, 2003). With permission.

framework can be used in problem-solving situations where there may be several potential solutions to consider, but also in situations which might be thought of as just completing tasks, and in particular those that involve several steps. The point is made that it is not just for major life problems, but also, and indeed principally, for everyday tasks. Over the course of the next few sessions, there is a focus on each of the steps involved, beginning in this session by looking at step 1, which is about identifying the main goal, something which is illustrated with some practical tasks using hypothetical scenarios.

Practical Task

Identifying the main goal. The aim of this exercise is to emphasize the importance both of recognizing that a problem of some sort exists *and* of specifying clearly the main goal that arises from the problem. A set of hypothetical scenarios are provided and using the blank goal management template, clients are asked to focus on identifying the main goal that

1. Main Goal_____

2. Alternative solutions	3. Pros	3. Cons

3. Decision:_____

4. Plan success failure

Step 1_____ ☑ ☐

Step 2_____ ☐

Step 3_____ ☐

Step 4_____ ☐

Step 5_____ ☐

Step 6_____ ☐

5. & 6. Remember to monitor and evaluate!
Are things going well? If not, do you need to change your plan?

Figure 6.2 A template used by clients to practice applying the Goal Management framework on both hypothetical and then real-life problems.

arises from the problems presented. The following is one example of the problem scenarios:

> You are in charge of organizing transport for a youth football team. On Saturday the team is due to play at a football ground which is 60 miles away. You usually go by bus. The kick off is at 3.00 p.m. Everyone knows to meet at your home football ground for 12.00 noon. It is Friday evening and the bus company has just phoned to say that all their drivers are on strike.

Further sample scenarios are provided in Appendix 6.2.

Homework

Clients are asked to use the goal management template in relation to one problem they are dealing with in their own lives, identifying the main goal they are facing with this problem. They are asked to use their individual session to discuss this task if necessary.

Session 6

Review of homework

The clients are asked to discuss the problems and main goals they identified. The importance of being clear about the main goal, and keeping this in mind over time is emphasized.

Education

- Goal management steps 2–5
  - (2) Identifying the possible solutions
  - (3) Weighing up the pros and cons
  - (4) Make a decision
  - (5) Monitor and evaluate progress
- Links to the mental blackboard.

In this session the focus is initially on helping clients to be more effective at thinking of a range of possible solutions for problems, avoiding a more impulsive approach. Use of the GM framework is illustrated with scenarios and then clients are able to practise using the framework in pairs, working on hypothetical scenarios.

The idea of a mental checking routine, using again the concept of the mental blackboard is discussed in relation to maintaining attention to the goal and steps towards achieving the goal. Clients are taught to develop a mental checking routine (based on the GMT described by Levine *et al.* 2000) using:

STOP!

THINK

CHECK THE MENTAL BLACKBOARD

Practical task

Practise scenarios in pairs using the framework.

Homework

Clients are asked to use the GM framework to achieve the goal of doing something they have never done before.

Session 7

Review of homework

The clients are asked to present to the group what they did to meet the challenge of doing something they had never done before. This often leads to a discussion of the importance of being very clear about the main goal. Clients often take the instruction to mean that the thing they should do must be something dramatic or difficult to achieve (e.g. do a parachute jump) and then struggle to identify anything they can do in a week. Other clients achieve the task well, by identifying a more mundane action or activity they have not done before. This provides a good opportunity to emphasize the importance of identifying the main goal and the solution generation (brainstorming). Similarly, clients may report failure to follow through with the goal, or complete steps, and again the idea of using the 'Stop–Think!' mental checking routine is emphasized.

The content of this group has evolved over time and no doubt will continue to do so. In part, modifications have been made in response to client feedback and the experience of the group facilitators over time. Furthermore, as more evidence has emerged in the literature with regard to strategies and approaches to managing both attention and executive difficulties, so this knowledge has led to the group being adapted.

Evidence for the effectiveness of the group

Is the group effective? As part of a holistic neuropsychological rehabilitation programme it is difficult to isolate the effect of a single group to determine whether it is effective (over and above other programme elements). However, a recent study by Miotto *et al.* (in press) involved an evaluation of this group format, run as a stand-alone intervention for a group of clients with evidence of executive impairment. This evaluation compared three groups of participants – one group underwent the attention and goal management programme, over a 10-week period. A second group received an information booklet that contained information about brain injury, covering cognitive, behavioural and social consequences and provided suggestions for cognitive exercises using the mental blackboard and problem-solving framework with the only instruction to read as carefully as possible the booklet and try to apply the exercises suggested, at home. A third group only received traditional treatment such as physiotherapy, when needed. This study showed that only the A&GM Group showed significant improvement on a number of target measures of executive functioning, including standardized neuropsychological assessments, a more practical multiple errands task and the Dysexecutive Questionnaire which samples everyday executive difficulties. This study adds to the evidence that group-based interventions focused on teaching strategies for improving problem solving/goal management can be effective in improving executive functioning.

As the attention and goal management phase of the Cognitive Group comes to an end, the emphasis shifts to managing memory problems, which is described in Chapter 7.

Case example: David

The following case example describes, David, a client who attended the A&GM Group as part of his programme and illustrates how strategies to manage attention and executive difficulties were applied in the context of his particular goals. At the age of 34, David suffered a cerebrovascular accident, resulting in a right internal capsule infarct. He was a

chemical engineer. Following an acute hospital admission, and then a period of in-patient rehabilitation, he returned home some four months post-injury. He had been unable to return to work, and had been medically retired. Eleven months post-injury David was referred to the Oliver Zangwill Centre. The main problems reported included:

- Mental tiredness
- Difficulty doing more than one thing at once
- Difficulty sustaining his concentration (either being very easily distracted or totally focused and locked into something)
- Bumping into things on the left
- Poor sense of the passage of time
- Difficulty thinking ahead or organizing things
- Difficulty initiating things (intends to do things, but doesn't do them).

Neuropsychological assessment revealed generally satisfactory verbal and non-verbal reasoning and memory skills. There was some evidence of persisting neglect, though only typically manifested in visually crowded and dynamic environments. There was however evidence of very significant problems with attention, affecting tests of visual selective, divided and sustained attention. He also demonstrated difficulties on tests of planning and strategy application. On a practical test of planning and preparing an unfamiliar meal, he completed the task, but nevertheless showed evidence of difficulties with attention (failing to notice an item he was searching for) and with problem solving (e.g. not responding effectively when unable to locate an item or when he noticed that an ingredient was not cooking fast enough). One of his hobbies was painting miniature military figures, which he had enjoyed doing while listening to the radio. However, since his injury he had found it impossible to do these two tasks at the same time, and, having become dispirited with his performance on the painting task following several attempts, had stopped painting. He was frustrated with his situation, and lacked confidence in himself. This also impacted on his relationship with his wife. David's lack of initiative and low confidence meant that the relationship with his wife lacked reciprocity.

In conjunction with David and his wife, the team constructed the following programme goals:

1. David will demonstrate an accurate understanding of the consequences of his brain injury consistent with his two-week detailed assessment report.
2. David will report an accurate understanding of the effect of his injury on his relationship with his wife and have identified strategies that he could use to manage his relationship more effectively.
3. David will demonstrate effective use of problem-solving strategies in social and functional situations as rated by himself, his wife and the clinical team.
4. David will demonstrate effective use of attention strategies in social and functional situations as rated by himself, his wife and the clinical team.
5. David will manage negative automatic thoughts in a range of family, social and leisure situations and rate himself as confident in specified situations.
6. David will plan his weekly schedule independently and complete 80% of activities successfully and without reporting excessive fatigue.
7. David will take responsibility for household budgeting and stay within an agreed monthly budget.

8. David will be engaged in a voluntary work trial and have a personal development plan.
9. David will be engaged in a physical leisure activity on a twice-weekly basis.

The goals reflect the processes of developing insight/awareness, managing mood and psychological adjustment, developing compensatory strategies for cognitive impairments, and applying strategies in functional, 'real-life' situations. As part of his programme, David attended the UBI Group, as well as working with his individual programme co-ordinator to develop a personal report of his own brain injury, the consequences and the strategies he uses to compensate for his cognitive difficulties. In David's case, the two main areas of cognitive impairment were attention and executive functioning. He attended the group described earlier, and worked with a psychologist to develop personally relevant strategies. Two approaches were taken to attentional problems. One was to use specific strategies to compensate for deficits and the other was to train performance on specific tasks in order to reduce the attentional load of these tasks. To compensate for difficulties with sustained attention, David learned to manage his environment better, to reduce distractions. A functional example was when having friends to visit selecting appropriate (e.g. quiet, ambient) music. He also developed a mental routine of checking his attention and where necessary refocusing his attention to the task in hand. In order to develop this routine initially he used an alarm clock that he set for 15-minute intervals. A good example of where cognitive and mood management strategies overlapped was when watching films. Pre-injury one of his great pleasures was watching a film together with his wife. However, post-injury it had become a struggle. He would find that after 20 minutes or so, he would start to find it hard to concentrate. He would then engage in a mental battle with himself, in effect trying to 'force himself' to stay with the film. But this battle in itself was a distraction and made it harder, so that he nearly always gave up watching, but felt bad. The approach used here was to use the mental check after 15 minutes to ask himself, 'Am I still concentrating? If not do I want to refocus my attention or take a break?' He also used video-recorded films more so that he could break and return to a film if he wanted. However, what he found in general was that by giving himself permission to take a break, he more often than not actually chose to simply refocus his attention. For some activities, he was aware that he was prone to getting 'locked into' the task. This happened most often if playing computer games. Here the problem seemed to be related to a dual-tasking problem, whereby he could not monitor peripheral stimuli and hence the passage of time effectively. In these situations he relied on using an external alarm (on an electronic organizer).

Two of the specific situations that David identified were difficult as a result of dual-tasking problems were playing badminton and painting his miniature figures. When playing badminton he found it difficult to play a shot and move to the next point in anticipation of the return shot. He also found it difficult to play and keep track of the score. Both of these he had done with ease before the injury. In this case it was hypothesized that the physical process of playing a shot was now taking more cognitive resources (it was not as automatic as it had been and required more conscious attention). The solution here was rather straightforward. David was simply encouraged to focus on the process of playing the shots and to practise regularly, to re-establish his skill level in the physical task. Then as his physical performance improved, he was able to gradually introduce the tasks of trying to think more about anticipating shots and also keeping the score. A similar approach was taken to returning to painting his figures. He began by doing short periods in very quiet

environments, and building up the physical skills. Then very gradually, classical music was introduced, then music with lyrics and then talk-based radio programmes.

With regard to problem solving or goal management, there were several areas of difficulty. Although some difficulty with planning had been identified in the standard assessments, there was evidence in most practical situations that he could identify solutions to problems. However he lacked confidence in his ability and also had major difficulties with initiation of intended actions. David was therefore trained in the used of the GM framework, which was practised with hypothetical problems and then personally relevant problems that arose during the course of the programme. David reported that he found the structured approach of the framework (which he could do mentally, rather than needing to write down) useful. It appeared that the formality of the process helped him to develop confidence that the solutions he derived were likely to be reasonable. He demonstrated use of the framework in coping with problems such as losing his electronic organizer, finding that some accommodation did not have his booking and was full, and in planning a weekend away with his wife. To compensate for his difficulties with task initiation, a self-instructional approach was adopted. David used a phrase that he said to himself, which was, 'Just Do It!'. This seemed to provide a sufficient attentional 'kick', that David was able to follow through on a greatly increased number of tasks. Once again a key issue was the role of mood factors in exacerbating the effect of the cognitive impairment. Armed with the strategies, the tools for coping, his confidence increased, and this in turn was a significant factor in itself in facilitating the initiation of actions.

In conjunction with the development of strategies, David was also focused on the functional goals, but of course as he developed confidence in the application of strategies, so he was able to apply them in a range of situations. He commenced a voluntary work placement in a Heritage Trust. He developed a planning system using his electronic organizer to schedule activities with more appropriate pacing. He took on the family budgeting role. He engaged in just one physical leisure activity per week. His increased level of confidence in problem solving and initiation meant that he felt he was less dependent upon his wife, which enabled him to engage in a more adult, equal relationship with her.

In summary, David presented with relatively circumscribed deficits in attention and executive deficits, which had a dramatic effect on his day-to-day functioning. In terms of Shallice and Burgess's (1996) model of the supervisory attentional system, David's main impairments could be thought of being in relation to the implementation of plans and monitoring of attention and action. This knowledge led to the development of strategies focused on improving initiation (e.g. the 'Just Do It!' strategy) and monitoring (e.g. the mental checking routine). He had less difficulty with actual planning, though lacked confidence in this, and then use of the problem-solving framework seemed to be helpful in the development of his confidence in this respect.

Appendix 6.1 Attention quiz

- Do you find it difficult to listen to someone talking to you when you are watching the TV or listening to music at the same time? Yes/No
  *What type of attention do you think this mostly involves?*_____
- Do you find it difficult to listen to someone and write at the same time? Yes/No
  *What type of attention do you think this mostly involves?*_____

- Do you find it difficult to listen to one person talking to you, if you are in a noisy crowd of people? Yes/No
  *What type of attention do you think this mostly involves?*_____
- Do you find it difficult to talk to someone on the telephone while you are watching television? Yes/No
  *What type of attention do you think this mostly involves?*_____
- Do you find your mind wanders when you are watching a film or reading a book? Yes/No
  *What type of attention do you think this mostly involves?*_____
- Do you lose track of what you are saying in the middle of a sentence? Yes/No
  *What type of attention do you think this mostly involves?*_____
- Do you find it difficult to find a phone number in a telephone directory? Yes/No
  *What type of attention do you think this mostly involves?*_____

Appendix 6.2 Examples of hypothetical problem scenarios used in the Attention and Goal Management Group

1. It is early evening. You have a group of friends coming over for dinner. You've spent the weekly shopping money on the meal. You start preparing the meal and find that the cooker doesn't work. Your landlord had said he would replace your cooker next week. The guests arrive in one hour.

2. A local charity nearly has enough money to buy some new computers for a school. They need just £200 more. It has to be raised by selling books and tapes. There is a car boot sale on Friday. You do not want to part with your books and tapes but promised to help out.

3. At present you are renting a house with three friends in the same area as your parents. The lease on the house expires soon and the landlord has refused to renew the lease, giving you until the end of the month to move out. You and your partner have a holiday booked in the Peak District for two weeks in just over a week's time. A job has been advertised internally at work, which would mean a promotion and an increase in salary, it would also mean moving to an office in a different town.

4. You have met with a friend to go into the city for the day shopping. After spending the morning shopping and having lunch together you realize that you are beginning to feel tired as you find yourself not listening to your friend's conversation and wishing that he/she would stop talking.

5. Your son and his wife are bringing your grandchildren over to your house for the day. You've planned to do a number of activities as a whole family together such as playing rounders, getting the paddling pool out and having a picnic together. However, halfway through the morning you realize that the noise and the pace of the activities are becoming too much – you find yourself getting irritated by the noise that

your grandchildren are making. You want to enjoy the rest of the day with the grandchildren, and don't want to upset them.

6. Every year I celebrate my birthday with Julie, a friend from school who has her birthday on the same day. We usually go out for a drink or a meal with other school friends. This year I'd really like to invite some of my new friends along. I have already mentioned my birthday to most of them. However, Julie really wants us to go away for the weekend as a group this year. This sounds like a nice idea to me but I really want to spend my birthday with my new friends too.

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Chapter 7

The Cognitive Group, Part 2: Memory

Jonathan J. Evans

Introduction

Memory problems are amongst the most commonly reported cognitive deficits arising from acquired brain injury. Any condition that affects the physical or functional integrity of the brain is likely to impact on some aspect of a person's ability to remember, as successful remembering involves many different interacting cognitive systems, including attention, memory and executive functions. Furthermore, mood disorders such as anxiety or depression, which impair concentration, also reduce the efficiency of memory.

Remembering difficulties disrupt the ability to participate effectively in activities of daily living, as well as social, leisure and vocational activities. For some, memory problems will be mild and cause only minor inconvenience in everyday life. Others, such as those with the amnesic syndrome that accompanies dysfunction in limbic system structures, may be severely disabled by their memory impairment. People forget to do things (e.g. take medication, turn off the cooker, pay bills, attend appointments, pass on messages), forget what they have been told, forget people's names, forget where they left things (e.g. keys, the car in the car park), find it difficult to remember routes or learn new procedures, have difficulty recollecting personal experiences and so on. Such problems lead to frustration, lowered self-confidence and dependence on others.

What does the evidence base suggest with regard to the rehabilitation of memory? One thing that has consistently been concluded is that memory does not seem to improve as a result of 'drill and practice' exercises (Sohlberg and Mateer, 2001; Cicerone *et al.*, 2005). Simply exercising memory does not lead to improvement in everyday functioning. Several systematic reviews of the cognitive rehabilitation literature in recent years have concluded that the use of strategies that compensate for memory deficits are the most effective approach to managing memory problems and increasing everyday functioning (Cicerone *et al.*, 2000, 2005; Cappa *et al.*, 2005). There are several forms of compensatory strategies, but they can most easily be split into 'internal' and 'external' strategies. Internal strategies are those that are used to maximize residual learning capacity of the client, and include strategies to enhance encoding of information into memory and mnemonic techniques. External strategies include external aids (such as diaries, electronic organizers, NeuroPage) and modifications to the environment. Replicating a previous study by Wilson and Watson (1996), Evans *et al.* (2003) surveyed around 100 people with memory problems arising from brain injury and found that

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the strategies most commonly used were external aids such as calendars, lists, notebooks and diaries, with the most commonly used mnemonic strategy being mental retracing of steps (to try to remember where a lost object, such as keys, had been left). Of note was the finding that there was limited use of other 'internal' strategies, and, at that time anyway, limited use of electronic reminding devices.

Memory problems and goal setting

Within the Oliver Zangwill Centre for Neuropsychological Rehabilitation programme, clients may have a goal specifically relating to the management of memory problems in everyday life. Consistent with the functional focus of goals set with clients, goals typically refer to clients successfully carrying out the majority of their daily tasks (e.g. use a memory and planning system to carry out independent living activities successfully on at least 80% of occasions). A goal such as this enables the client and team to focus on identifying the specific tasks that the client has to complete in everyday life (focusing on those with which he/she is having difficulty). Reference to a memory and planning 'system' highlights the fact that for many clients there will be a range of strategies or aids that are used in order to manage many different everyday remembering tasks.

Kime (2006) provides a very useful, practical account of how to help people compensate for memory deficits. Her approach is the same as that taken within the Oliver Zangwill Centre programme whereby the remembering needs of the client are first established and then a memory system is developed with the client to meet those needs. Within the Centre, it is most commonly an occupational therapist who takes the lead in relation to this goal, but several members of the team may contribute. The aim is to highlight current demands for remembering things in daily life, with a particular focus on the specific tasks with which the client is having difficulties. Furthermore there will be a focus on the remembering demands associated with other goals such as those relating to vocational, social and leisure activities, as well as other activities of daily living. For some clients the system of strategies and aids will develop as the programme progresses, taking into account increasing awareness and increasing demands as the client begins to engage in more complex activities.

Memory groups

A number of writers have discussed the potential value of doing memory rehabilitation in a group context. Most recently Craik *et al.* (2007) described the use of a group format for cognitive rehabilitation in the elderly. This study involved several cognitive modules, including a memory module, carried out with groups of five to six participants. Other modules focused on goal management and psychosocial training. The focus of the memory training module was described as 'learning a variety of strategies and techniques to improve organizational and memory skills' (p. 133). The sessions included education on the complexity of memory and its relationship to brain function. Participants learned about different forms of memory and about factors affecting remembering and forgetting. There was a focus on developing awareness of individual memory slips, then a focus on use of external aids and then internal strategies related to encoding information in a deep and meaningful way. Homework tasks were used to prompt practice at use of strategies and aids. Craik *et al.* found evidence that the overall cognitive group programme resulted in improvement in some aspects of both secondary memory and strategic processing. This group format combining education with a focus on both internal and external strategies was also

described by Wilson and Moffat (1984), Berg *et al.* (1991), and Evans and Wilson (1992). The great benefit of a group format is that it provides the opportunity for clients to develop awareness of problems and strategies by learning from their peers. In relation to developing awareness, the opportunity to hear others talk about everyday problems prompts some clients to think about their own difficulties. Furthermore, for some clients, hearing others accepting that they have difficulties can make it easier to acknowledge their own problems. Similarly, with regard to use of strategies, hearing another client discussing how useful a particular strategy or aid is may convince them to try out an aid which they may be more reluctant to do just on the recommendation of a professional. There can also be an element of specific feedback from peers that facilitates awareness and peer encouragement or pressure to try things out, which can be helpful.

Therefore, taking into account the evidence base relating to which approaches to memory rehabilitation are most effective for people with acquired brain injury, the general focus of the Oliver Zangwill Centre on increasing participation in valued everyday activities and the evidence that group formats can be a useful approach to cognitive rehabilitation, a memory group format was developed and has been used since the Centre was founded.

The Oliver Zangwill Centre Memory Group

As discussed in Chapter 6, the Memory Group is set in the context of the broader idea of a 'cognitive group'. The Memory Group combines three broad components – education about memory and memory problems, internal strategies and external aids. The group typically runs once a week for up to 2 hours, for a period of about 6 weeks, though this will be flexible depending on the needs of the participants and other timetabling constraints. Each client has at least one additional individual 60-minute session each week to review materials from the group, develop understanding of how topics discussed in the group are of relevance him/her and to identify how to apply strategies discussed in the group in everyday life.

In the first session the clients are introduced to the objectives of the group which are:

1. To learn about memory and develop an understanding of your own memory problems
2. To understand the purpose behind some of the assessments you may have done
3. To discuss different memory strategies
4. To practise memory strategies
5. To apply and evaluate memory strategies in relation to your problems.

At the end of each session, the group is asked for a volunteer who will agree to give a brief summary of the material covered at the start of the next group. Clients are provided with handouts, with space to make additional notes.

Education about memory

The education component may be delivered first as a broad background, with the subsequent topics being covered week by week. Or it may be provided session by session for each specific topic, so for some groups of clients each week is made up of educational, experiential (trying our strategies) and reflective (group discussion) components. This varies depending on the nature of the clients who are participating (i.e. depending on the severity of cognitive impairment of the participants). Here we describe each component as if delivered week by week. Clients are introduced to the different forms of memory, including short-term or working memory and long-term memory. The differences between semantic and episodic,

implicit and explicit, and retrospective and prospective memory are explained. In addition, the various modalities of memory (visual, verbal, olfactory, gustatory, kinaesthetic) are described. The parts of the brain involved in the different forms of memory are explained with reference to basic diagrams of the brain. The different stages of remembering are discussed (i.e. encoding, storage and retrieval). Participants are then introduced to the different forms of memory disorder, the terminology being explained (e.g. amnesia, post-traumatic amnesia, anterograde amnesia, retrograde amnesia, confabulation).

The next section of the group discusses how memory is assessed. An explanation of how the different forms of memory are assessed with different tests is provided. This is only done with clients who have already undergone assessments (so as not to undermine the testing process). The aim is then to support clients in developing a better understanding of the content of their detailed assessment report.

The causes of memory problems are described and it is illustrated how different forms of acquired brain injury (e.g. head injury, stroke, anoxia, encephalitis, tumour) may lead to memory impairment.

Next, the many factors that can affect remembering in addition to brain injury are discussed, including:

- Attention and concentration
- Speed of processing information
- Planning and organizing information
- Visuo-spatial and perceptual skills
- Language
- Frustration/negative thoughts
- Stress/anxiety
- Fatigue
- Drugs/alcohol etc.
- Motivation
- Environment.

The most common forms of memory problems after brain injury are described (e.g. difficulties remembering things after a delay, learning new things), but there is also an emphasis on those forms of memory that are usually intact (e.g. remembering how to do things, remembering things from the more distant past). This leads to a discussion of the more specific and common everyday manifestations of memory problems including:

- Forgetting what's been said
- Asking the same questions over and over
- Repeating stories or activities
- Forgetting names
- Forgetting where things have been left
- Learning new routes and getting lost
- Forgetting to do something
- Forgetting a change in routine
- Not planning or following through with plans
- Being disorganized
- Difficulty noticing or remembering your memory difficulties.

Clients are encouraged within the group context to describe their own memory difficulties. To facilitate this, clients are invited to complete a 'Memory Quiz', which is a questionnaire on which they are asked to identify which tasks they have difficulty with, and also to outline whether they do anything to try to help themselves remember things. The questionnaire includes:

- The date
- The month
- The names of people you have known for a long time
- The names of people you have met once or twice
- The faces of people you have known for a long time
- The faces of people you have met once or twice
- How to get to somewhere you know well
- How to get to somewhere you have been once or twice before
- Where you have put something
- What you have been told
- What you have read
- Taking your medication
- Things you have to do (general)
- Things you have to do (appointments)
- Other problems…

A key part of the process of clients developing a better understanding of their own memory (and other cognitive) difficulties is the work they do as part of the Understanding Brain Injury (UBI) Group (Chapter 5), supported by individual sessions with a member of the team. Clients are provided with self-monitoring sheets and asked to try to record examples of problems that arise, noting the type of problem. Clients are also asked to try to understand what type of impairment (e.g. memory, attention, planning etc.) might have contributed to the problem that arose. This is not always easy for the client, but they can sometimes be supported to think back to the situation and reflect more on the factors that have contributed to situations that arise.

Towards the end of the general education component, the focus turns to the topic of how to manage memory problems. The fact that memory does not seem to be like a muscle that can be exercised in order to make it stronger is discussed, leading to an outline of the main ways in which clients can best manage memory problems in day-to-day life including:

- Understand your own memory problems through education and effective monitoring
- Capitalize on strengths within your memory system to overcome any weaknesses
- Find and use strategies which work for you and use them consistently
- Adapt the environment
- Be planful and use routines
- Pace yourself to avoid fatigue.

Memory games can be useful, not in the sense of exercising memory, but for the purpose of illustrating different aspects of memory and for stimulating discussion of the application of strategies. Games such as Kim's game (where objects are placed on a tray and viewed for a short period, the tray is covered and participants have to recall what was on the tray) or

Pairs/Pelmanism, the card game in which a pack of cards is spread out face down and players try to turn up pairs with the same symbol, can be useful. Both games can be used to illustrate how strategies can be applied to enhance performance, reinforcing the main message from the group that the most effective way of dealing with memory problems is the use of strategies that compensate for impaired memory. In the group described by Evans and Wilson (1992), participants often commented that they enjoyed the games and that having some success on challenging memory tasks (and getting better at the games over the course of the group) was a boost to their confidence.

The rest of the group is focused on looking at strategies that can be applied in a range of situations and begins with 'internal' strategies and then goes on to discuss external aids and modifications to the environment.

Internal strategies

The second phase of the Memory Group focuses on internal memory strategies. These are introduced as techniques that may, in some situations, help encode information more effectively, so making it easier to recall later. It is emphasized that in order to be useful, such techniques need to be used regularly and applied with effort. Some of the techniques reflect more general principles of learning (e.g. making associations) and can be applied in many different situations, but others are very specific and only useful in very specific learning situations (e.g. PQRST). The techniques are briefly described below, with information on why they are included, and, where available, with reference to evidence for their effectiveness.

Making associations

One of the most robust findings in memory research is that the more meaningful information is, the easier it will be to recall (Craik and Lockart, 1972; Baddeley, 1999, p. 85). What is meant by 'meaningful' is something that is relevant to the person and is easily linked or associated with prior knowledge. This general principle of enhancing memory by making information more meaningful and trying to actively link it with previous knowledge is described. Practical examples are provided including:

- Remembering to carry out a new activity by linking it to an existing routine, e.g. taking medication with meal times.
- Learning the name of someone you have just met by thinking of somebody you already know with the same name (a friend, or movie star).
- Leaving your walking boots by the door, to remember you are going out walking with a friend today.
- The PQRST technique (described later) is a means of deepening the level of processing of information by establishing a set of questions to answer while reading information.

Visual imagery

This refers to making best use of residual skills using multiple modalities to aid recollection (particularly relevant if verbal memory is impaired). Many of the studies of meaningfulness referred to above showed that information that is easily imaged is much more easily remembered than information that is purely verbal or abstract. Therefore if one system is damaged, or if both verbal and visual memory are impaired, it is a good principle to try to make use of both systems, by trying to use visual imagery where possible. Practical examples include:

- Learning names, e.g. people or streets – Learning the names of new people is a difficult task because it involves forming an association between two sets of unique, arbitrary information (a face and a name). Visual imagery can be used in a number of ways. For example it may be possible to link a feature of the person's appearance to their name in some way. Clare *et al.* (2003) used this technique, in combination with other techniques, to teach a man with Alzheimer's disease to learn the names of people in his social group.
- Routes – The most basic wayfinding strategies include use of landmarks and formation of a 'cognitive map' (a mental map of the route). Good wayfinders make use of both of these strategies (Kato and Takeuchi, 2003). Although these basic strategies are likely to be familiar to most people, it may be the case that some people did not pay a great deal of attention to this issue prior to their injury and may also not think to use such strategies in a conscious way after their injury. However, a recent study by Lloyd (2006) found that encouraging patients to use either a landmark or cognitive map strategy did not enhance the benefit they received from an errorless learning approach to route learning (see below for a discussion of errorless learning), so it may be that specific encouragement to make best use of landmark and cognitive map strategies is only relevant for some people. For those with severe memory impairment such techniques will simply not be relevant as the person would be unable to remember the information with or without the use of the strategy.
- Things to do – People are encouraged when creating an intention to do something at a later time (e.g. post the birthday card on my way to the shops), to use visual imagery to try to imagine themselves doing that task. A key task is to try to form an association between a cue (e.g. something in the environment, such as the postbox) and the action.
- Shopping lists – Although visual imagery can be used to help remember items that need to be bought, we would usually advise that a written list were used.

Chunking

This is the principle that working memory works more efficiently when information is 'chunked' (e.g. a telephone number is remembered better as 781 267 than 7 8 1 2 6 7).

Mental retracing

Retracing your movements, activities and thoughts in your head, in sequence, usually for the purpose of remembering where you put something. An example is used:

- Where did I leave my diary?
  - Before I came to this room, I checked in at reception, before that I was in the car. Did I leave my diary at reception? No, I signed the book and I didn't have it with me there. Did I leave my diary in the car? I can't remember whether I took it to the car. OK, where was I before the car? I was in my flat. I remember I picked up my diary, I locked the door behind me, and I had my diary in my hand as I walked down the stairs. I put it on the passenger seat when I got in the car.
  - My diary is in the car.

Errorless learning

It is noted that people traditionally say that we learn by our mistakes and that if you make a mistake, you remember it and then next time you are less likely to make the same mistake again. However, a considerable amount of research has shown that for people with memory deficits, it is best to try to avoid making errors while trying to learning something (see

Kessels and DeHaan (2003) for a meta-analysis of this research). This is because for someone who is memory-impaired, it is likely that errors will not be remembered, and in fact, once made, errors are more likely to be made again (as a result of unintentional priming). Practical examples illustrated include:

- Have detailed instructions when learning a new task, or how to use a new piece of technology, and follow them until it becomes automatic.
- When route finding to a new destination, wherever possible have someone with you the first few times, and mark down significant landmarks.

PQRST

This is a study technique that can be useful in some specific circumstances. It can be useful in traditional study environments (e.g. having to remember the content of a chapter or paper) and in more informal situations such as remembering newspaper articles for conversation in a social environment. The letters refer to:

- **Preview** – look over the information, what is it generally about?
- **Question** – what questions are you hoping to answer by reading the information?
- **Read** – read!
- **State** – state the answers to your questions.
- **Test** – how well do you remember the information in the article?

If this technique is likely to be useful for a client, then they are trained in its use. We have found that it is not relevant for the majority of clients, but for a small subgroup it has proven to be very useful. One example was a man who had been studying at university and suffered an anoxic event during recovery from anaesthetic (having undergone orthopaedic surgery). His memory was severely impaired as a result, but otherwise he was quite intellectually intact. He was determined to return to university, though his former degree course was considered too demanding. He enrolled in a different degree programme and found that the PQRST technique was very useful for learning material for exams. He was successful in obtaining his first degree and then subsequently a Masters degree.

Mindmaps

This is another technique that is also primarily a study technique, but one that can also be applied to other situations. Essentially, a mindmap involves putting the information to be remembered on to one sheet of paper, using a 'tree-like' representation of information, with words, images and colours and then remembering the mindmap (with both verbal and visual memory), so as to remember the information content. The aim is to use multiple modalities (verbal, visual, spatial) to represent information and hence to make it more memorable. The act of creating the mindmap in itself means that the material is processed at a 'deeper' (i.e. more meaningful) way. Some examples of how mindmaps are used by the general population can be found on the website of Tony Buzan, who is most associated with the development of this technique (www.buzanworld.com). In our experience, mindmaps are, like most of the mnemonics, not appropriate for use by people with significant memory impairment in relation to most everyday remembering tasks. However, for those people who are returning to education, or in a work situation where new information has to be learned, then they can be useful. As with PQRST, the main use of mindmaps is in study situations where a large amount of information on a topic has to be remembered for an exam, but again they have application for learning information

about news stories, or even procedures and could in theory be used in a wide variety of situations.

Other Mnemonics

There are a range of other mnemonic techniques that have relatively limited use, though can be helpful when learning very specific information. Some of the examples discussed in the group include:

- Changing numbers to letters, e.g. PIN number 1278 – **O**ne **T**iny **S**weet **E**lephant (First letter of word corresponds to first letter of number – One Two Seven Eight), or 1534 (number of letters in word corresponds to number in PIN – a field has mice).
- Rhyme mnemonics, e.g. To remember what happens when the clocks are changed – 'Spring forward, fall back'.
- First letter mnemonics, e.g. The lines of the stave E,G,B,D,F (**E**very **G**ood **B**oy **D**eserves **F**avour) or Things you need to buy – **C**arrots, **O**range juice, **M**ilk, **B**read (COMB).
- Creating a story to remember words/items/spellings. For example for a shopping list including Shreddies, caster sugar, coffee and toothpaste you might create a story such as 'In the morning I get up and eat my Shreddies with caster sugar and have a cup of coffee. Then I clean my teeth.'

External memory aids

The third phase of the group focuses on external memory aids. It is noted that most people, brain injured or not, use external memory aids such as calendars and diaries to remind them of appointments, and shopping lists. There is often discussion that people associate use of memory aids such as diaries and to-do lists with the work environment and sometimes those who have used memory aids regularly before the injury in the work context do not spontaneously use them after a brain injury, even though there may be greater need. Nevertheless we know from the study by Evans *et al.* (2003) that those people who have used memory aids premorbidly tend to make greatest use of memory aids post-injury. This suggests that familiarity with memory aids and perhaps a sense that use of memory aids is 'normal' facilitates use post-injury. However, for some people, it seems that because they have memory impairment, responsibilities for remembering are, in effect, taken away and there is very little expectation or demand on the person to remember things. This therefore means that they have little to remember, so don't use a memory aid, but failure to use memory aids means that the individual is not likely to be successful in remembering tasks, so reinforcing an assumption that the person should not be given responsibility for remembering things. This 'chicken and egg' situation has to be addressed by encouraging and supporting clients to develop their use of memory aids. For some this can be done by selecting an aid and then thinking how it could be used, but for most the approach should be one in which clients are supported to identify something that they want to be more independent in remembering (e.g. taking medication, appointments, things to do, work tasks, meals to cook, picking up children from school, passing messages, feeding pets). Clients are encouraged to think of themselves developing a 'memory-system', which may have a number of different elements that enable them to remember the various activities. They are then introduced to a range of different memory aids including:

Diaries/notebooks: it is noted that a diary may function as a journal or as an appointment diary. Diaries come in many different sizes and styles and clients are encouraged to

consider what will suit their needs best. A simple notebook can be used to record notes during the day which may be transferred to a diary.

Filofax: a filofax, or personal organizer, combines the functions of a diary, a to-do list, address book and various other possible functions.

Calendar, wall chart/planner: these are useful if you spend a lot of time in a particular place (home or work). They have the advantage of being visible and so information is easily accessible. A major disadvantage is that they are not portable.

Basic alarms: alarms can be delivered by mobile phones, alarm clocks, watches, kitchen timers etc. They are useful for regular reminders (e.g. check your diary or to-do list), or for one-off reminders if you can remember the information content (e.g. remember to stop off on the way home from the Centre to get some milk).

Post-it notes: these are useful for quick notes that can be placed in visible places to act as reminders, but one has to be careful that too many are not used at once as they can become disorganized.

Pillboxes or dosset boxes: forgetting to take medication is a common complaint of people with memory impairment. For some the problem is not only failing to take medication, but may also be one of forgetting that the medication has in fact been taken, with the risk that the person will take another dose. One aid that is helpful is the pillbox, sometimes referred to as a dosset box. It is normally a hard plastic box or grid of compartments with sliding clear plastic windows that are labelled with days of the week. One dose of pills is put in each compartment allowing the client and family to know whether or not doses have been taken. A limitation of pillboxes is that they may only act as a reminder if they are in view, and so for some people it will be necessary to combine a dosset box with an alarm (e.g. watch alarm) or associate taking medication with an aspect of a person's routine (mealtimes or bedtime are most common).

Dictaphones: a dictaphone can be used like a 'spoken notebook', i.e. it can be carried in your pocket and things can be recorded onto it as they happen. Dictaphones are useful for people who have difficulty writing things down quickly. Wilson *et al.* (1997) describe the use that JC, who has an amnesic syndrome as a result of a stroke in the area of the retrosplenium, has made of several memory aids including a dictaphone, filofax and a watch alarm. Throughout the day JC records notes to himself describing activities he has done or future appointments and he then transfers these notes to his filofax at the end of each day.

To-do list: a simple list of things to do can be very useful in helping manage everyday tasks.

Electronic organizers: there is now a wide range of electronic organizers, or personal digital assistants (PDAs) commercially available. These are particularly helpful for those who have used such devices prior to their injury or have the residual ability to learn how to use them. Some are very complicated, with multiple functions, which can put off some clients, and it is important to think carefully about what functions are required and ensure that the organizer that is selected only includes those functions if possible.

NeuroPage: this is a system that uses a radiopager to alert the user and deliver a reminder message, usually relating to a task that has to be carried out at a specific time. This system has been extensively evaluated. Wilson *et al.* (2001) showed in a randomized controlled trial that NeuroPage was effective in increasing the ability of people with memory and executive impairment arising from a wide range of neurological conditions to carry out everyday tasks that were, in baseline conditions, frequently forgotten. Using

a single case experimental design, Evans *et al.* (1998) demonstrated that the NeuroPage was highly effective in improving the performance of a woman (RP) with severe attention and executive dysfunction (but normal memory functioning). RP found it difficult to initiate actions and also to maintain attention to a task (and hence was very easily distracted). The NeuroPage was highly effective in improving her ability to both start and complete activities at the right time. In the UK, a NeuroPage service has been established and provides a reminding service to people with memory impairment across the UK (see www.neuropage.nhs.uk).

NeuroText: the NeuroPage service is available in SMS text format whereby reminders are delivered via an SMS text to a mobile phone rather than a pager.

Mobile phones: these can usually be set up to deliver an alarm and a reminder message.

Organizing the environment and use of routine: some people are able to live successfully in a cluttered and disorganized environment, but to do this successfully requires a good memory for where things have been placed and when things need to be done. For example, if you have a bill to pay, if the bill is not easily accessible (visible even) or if you do not have some other reminder to pay it, that bill may go unpaid if your memory is poor. Similarly, if you are used to putting your keys down anywhere in the house, unless you remember every time where you left them, you are likely to lose them regularly if you are memory-impaired. So, being organized with your filing or how you store things like bills to be paid is very important for the memory-impaired person. A very simple strategy for things like keys or a wallet/purse is to always keep them in the same place. Although use of routine is not really an external aid, it is a way of interacting with the environment that reduces remembering demands. Always taking medication with a meal will enable the person to learn the association and so given that having a meal is automatically prompted (by time or by feeling hungry), so medication can be more easily remembered.

Developing an individualized memory system

As clients are participating within the Memory Group they will also be working with members of the team to establish what their specific current and future needs might be. The term 'needs' here relates to what it is that the client is trying to achieve with which his/her memory problems are interfering. In establishing 'needs' it is recognized that it is not possible to anticipate every single situation in which someone is likely to have problems. Instead, priorities have to be identified, those being the tasks that are critical to the achievement of the client's current goals. Once those needs are clearly identified the client works with the team to build a system of aids and strategies. Sometimes this will in fact just be one aid, but often there will be more than one aid or strategy used.

It is also recognized that needs may change over the course of the rehabilitation programme or once the programme has ended. Part of the function of the Memory Group is therefore to provide clients with a way of approaching tasks in the future. In one sense they are provided with a tool box of strategies from which they can draw in the future. In another sense the group aims to simply reinforce the message that the task for them is to be aware of what they need to remember, be aware of their memory difficulties, anticipate the specific problems they may have in practical situations and to identify and implement the appropriate strategies to meet their needs. Of course some clients will be able to use the group in this way, whilst others will always need support to adapt to new situations as they arise.

One example of someone for whom a range of strategies was developed is that of Mark. As a result of a mountain-bike accident in which he fell about 1000 feet down a mountain in Switzerland, Mark suffered a severe head injury. He was 30 years old at the time of his accident. An early CT scan revealed evidence of oedema and a subdural haematoma. He also developed meningitis whilst in hospital. Following stabilization he was transferred to London where he underwent in-patient and then out-patient rehabilitation. He improved physically and was able to return to independent living. Seven months post-injury he was referred to the Oliver Zangwill Centre. At that time he had not returned to work and there was great concern that persisting problems with memory would affect his ability to cope in the work environment. Detailed assessment revealed significant impairment of both verbal and visual memory that was evident on tests of recall and recognition. There were milder difficulties with attention (ignoring distraction). Performance on tests of executive function was affected, but this was thought to be the result of his memory problems. There were mild high-level communication difficulties in that he would sometimes drift off topic in conversation. Mark's goals for rehabilitation were:

- to demonstrate an awareness of his strengths and difficulties through written form consistent with his neuropsychological profile and be able to describe how those problems could impact on his domestic/social/work life.
- to identify whether he can return to previous employment.
- to demonstrate competence in negotiation skills as rated by self/work colleague.
- to manage his own financial affairs independently.
- to develop a range of leisure interests.

The most important goal for Mark was to return to work. Prior to his injury he worked as an international property underwriter for a large insurance company based in the City of London. This was a job with a very high level of financial responsibility. Mark's employers were very supportive and keen to help him return to work, but were also concerned to be sure that he was capable to doing the job effectively. Within the programme Mark began to work on the UBI goal by attending the UBI Group and working with his individual programme co-ordinator (IPC) to develop his portfolio. At the same time Mark attended the Memory Group and was supported to begin to appreciate the nature of his memory difficulties. This was an emotionally difficult process – as he came to understand his difficulties his concern regarding the implications regarding return to work grew. Mark was supported to create a detailed job description, and, in addition, he was set the goal of identifying in what way his memory difficulties might impact on his work. This revealed that although his job had significant responsibilities, a major advantage was that much of the job was done in discrete, relatively short episodes, which made limited demands of the aspect of Mark's memory that was impaired. Brokers came to him with a view to buying insurance (e.g. for a large factory or oil refinery). A price was negotiated and once agreed the paperwork signed there and then. Mark identified that the most important aspects of his job on which memory problems might impact were his knowledge of risks (e.g. what countries, or companies, were too high a risk) and he also identified that one of the things that had made him successful in his job were his social skills – Mark got on well with people and part of that was his ability to remember things about the people with whom he did business. To address the first issue, the team created with Mark a database into which he recorded details of insurance losses published in the industry newspaper. It seemed the act of reading the newspaper and recording details of losses helped consolidate his knowledge

of information relevant to judging risk and so making insurance decisions. To address his issue of knowledge of the brokers who came to him with business, he used a 'contacts' record-card system that he could update as and when there was something important about someone to record. Mark was then supported to identify, with his manager, a series of stages in a return to work process. These were designed to enable both Mark and his manager to be confident that he was able to competently perform his job (without placing the company at great financial risk). The stages involved initially shadowing a colleague and being able to demonstrate to his manager that he had good knowledge of factors relevant to insurance underwriting decisions. Next, Mark was given limited underwriting authority (such as being able to agree limited mid-term changes to an insurance policy), but all his paperwork had to be counter signed by his manager. He was then given authority to renew policies, then take on new business with his paperwork again being counter signed, and finally he was given full underwriting authority. Mark returned to full-time paid employment and is still in employment several years later. Not all employers are as helpful or accommodating as Mark's. In Mark's case, his willingness to acknowledge both the potential impact of his memory problems, and to comply with a return to work process that meant that he had to accept a level of supervision that he had not previously required, were both central to the success of the rehabilitation programme. This was by no means easy for Mark. The psychological support of the team and his peers on the programme, as well as his family and colleagues, seemed critical to his willingness to accept what was a considerable threat to his sense of self (i.e. the possibility that he would not be able to successfully return to work).

Conclusion

Interventions aimed at addressing memory impairments after brain injury must be set in the context of the personal goals of the individual. This is the major focus of the Memory Group – providing clients with the tools to compensate for memory deficits in everyday situations. The case of Mark illustrates the importance of clearly establishing how memory (or any other cognitive impairment) will impact on work (or other aspects of daily life) and then developing a system of aids and strategies that will effectively compensate for a person's impairments. But it also highlights the fact that such practical strategies may also require considerable work to help the person understand their difficulties and accept them, something that may require considerable psychological support.

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Chapter 8

The Mood Management Group

Kate Psaila and Fergus Gracey

Introduction

The Mood Management Group is an integral part of the programme at the Oliver Zangwill Centre for Neuropsychological Rehabilitation. Although clients attend the Psychological Support Group and individual mood sessions, it is clear that clients experience common emotional sequelae (Williams and Evans, 2003) that benefit from a group approach.

Whilst the Psychological Support Group (Chapter 9) provides a protected space and time for clients to support one another, to reflect and to apply cognitive and communication skills in a group setting, the Mood Management Group provides a 'normalizing', psychoeducational and strategy focused approach. The group process of sharing experiences and reflecting on how learning in rehabilitation may apply to oneself or others is still important, but is less central than in the Psychological Support Group. Practically, it enables clinicians to share a greater amount of information with clients than possible in individual sessions. As a result of this group, it is hoped that clients have a greater understanding of their own and others' emotional goals, challenges, strengths and strategies, and can share perspectives and develop self-awareness. This aims to empower individual clients so the group members can support each other more effectively.

Aims of the group

In the Centre policies and procedures, we describe the aim of the group as follows:

> The Mood Management Group is aimed at providing clients with an opportunity to develop an awareness of problems they may have in mood and behaviour and for developing skills and strategies for coping with such problems.

This is done by providing information, supporting sense-making, and helping clients develop skills to deal with changes in their experience and expression of emotion. This is done by:

- Normalizing emotional reactions, particularly as a result of brain injury and showing that these reactions are understandable.
- Enabling clients to formulate their own understanding of their reactions to their injury, which in itself may lead to change.
- Facilitating discussion with other clients and sharing of experiences.

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- Provision of a 'toolbox' of strategies to provide clients with experience of trying different ways of coping with emotional challenges.
- Empowering and encouraging client choice in rehabilitation strategies.

Organization and structure

The Mood Management Group consists of twelve, one hour long, weekly sessions. The group is facilitated (ideally) by two members of psychology staff and has been any combination of clinical psychologists, and/or supervised assistant or trainee psychologists. The structure and pace of the group is flexible and determined by the clients' needs, and that of the overall milieu. For example for one intake, relaxation was practised weekly within the session for 10 minutes.

Group sessions comprise of 10 minutes at the beginning to review homework/recap on the previous week, 40 minutes to cover presentation of key topics (e.g. the brain and emotions, or the adjustment process), group discussion, practice of exercises (e.g. different relaxation techniques, mindfulness meditation, attention control, emotional problem solving) and application to real-life examples, with 10 minutes to recap and summarize the learning points at the end. Personal reflection is facilitated through the questions 'What is your personal take-home message?' and 'What is the next step in developing this?' Clients are encouraged to use a summary sheet (see Appendix 8.1) to support and structure this reflection and also to help generalization. The group is based on a general cognitive-behavioural model and related techniques, supporting clients to develop awareness, emotional problem-solving skills and a reflective ability, and to address unhelpful meanings associated with the emotional consequences of their injury. There are a number of educational points that the facilitators aim to get across to the clients each session, however, this group also has a strong discussion component and encourages clients' learning from each other, and trying out strategies within and outside the group. Clients attend the Mood Management Group alongside attending individual psychological therapy sessions.

Information is presented via handouts and/or PowerPoint slides, depending on client preferences and abilities. Clients are provided with copies of all the slides for each session, with space to make notes. Flip-charts or whiteboards are often used to make notes of discussions and to illustrate examples. There is some overlap between the contents of other groups, for example the Understanding Brain Injury (UBI) Group also covers a little about how the brain manages emotions, and the Cognitive Group covers problem solving or goal management, also used as an approach to emotional coping. Clients are encouraged to make links between their individual and group work. This is done explicitly in the first few weeks 'Does this link with other areas of work you're doing in rehab at the moment, for example in the Cognitive Group?' or 'How does this link with the goals you are working towards?' Progress made in the group towards individual client's agreed goals are fed back to the team in each clients' goal planning meeting.

Syllabus

The group is split into three main sections: (1) week 1: introduction and topics of interest, socializing to the group and finding out what they want to get out of it, (2) weeks 2–5: what affects mood and emotions? information and formulation and (3) weeks 6–12: strategies and techniques, problem solving and experimenting. These sections have

been presented serially in this order, but often, where clients may struggle with the seminar type of group, more emphasis is placed on strategy practice so section 3 runs in every group, after covering an introduction to the topic. Where possible techniques that link with the topic are presented. Homework is sometimes given, often involving self-monitoring, identifying different coping styles used, noting the emotional responses of others and whether they coped well or poorly. However, as clients have significant amounts of homework from individual sessions elsewhere on the programme, this is not emphasized as much as it would be if the group were run as a stand-alone out-patient group.

Week 1: introduction and topics of interest

Clients are welcomed to the group. The first exercise is spent finding out what the clients would like the group to learn about. This is usually presented as a 10-minute exercise, initiating client discussion about emotions. The standard aims of the group are then assimilated into these: to increase the clients understanding of the emotional consequences of brain injury, to learn about factors affecting mood and emotions, to understand their own emotions better, and to learn ways of helping to manage or change emotional consequences.

The next topic addressed is 'What influences mood and behaviour?' A group discussion is encouraged. Contributions are categorized into the following areas:

- Type of injury or damage
- 'Personality' before and after the injury
- Adjustment to changes and losses
- Coping style
- Environment and Triggers, including roles and relationships.

A PowerPoint slide is used to present these topic titles as a biopsychosocial model. This exercise prepares the background for the next few weeks when the areas are discussed in more detail. During this session emotion is normalized; it is explained that emotional and behavioural changes are very common following any form of brain injury as the brain is the control centre of our emotions.

The cognitive model is used in this group to help clients think about emotional processes. It is easy to conceptualize, it facilitates strategy use and there is emerging evidence for its efficacy following brain injury (e.g. Alderman, 2003; Khan-Bourne and Brown, 2003; Williams *et al.* 2003a, 2003b; McGrath and King, 2004; Tiersky *et al.*, 2005; Gracey *et al.* 2006; Dewar and Gracey, 2007). A key point here is that there is variability in emotional and behavioural expression depending on the situation, and understanding what underpins this variation can help with predicting, planning and making changes to improve mood and the outcome of specific situations.

The cognitive-behavioural model is introduced (Greenberger and Padesky, 1995, p. 4). The aspect of cognition is added to this model in order to acknowledge the impact of the brain injury on the client's experiences and may impact their thoughts, feelings, behaviour and physical responses. In conjunction with the biopsychosocial model presented earlier, the cognitive model of emotion provides a simple memorable concept for clients to think about their emotional reactions in the moment. This is introduced with an everyday example.

Week 2–5: what affects mood and emotions?

Type of neurological damage

The 10-minute recap of the previous session provides an introduction to this topic. This session involves presentation and discussion of how the type of neurological damage impacts on emotion and behaviour. The aim is to provide some information on normal emotion, and the brain's control of this. It is explained that the brain is the seat of our emotions, and that emotions are essential for survival. Specifically covered is how frontal, temporal and limbic areas interact in the experience and expression of normal emotional responses. Evolutionary ideas about the survival roles of fear, aggression and depression are often used to facilitate the idea of emotions being normal. The impact of cognitive difficulties (especially in executive, attention and memory functioning) on the brain's ability to process emotions effectively is raised. A model of the brain is used in this session, as are the pictures from the UBI Group (Chapter 5).

The influence of the development of the frontal lobes in controlling our behavioural and emotional responses, and as a skill that is learnt throughout our life is discussed in more detail. Clients can usually relate to the processes children go through of learning to initiate or inhibit behaviour. This provides a rationale that relearning control of strong emotions or impulsive behaviour, socially appropriate ways of expressing feelings or strategies for understanding others' feelings may be necessary following a brain injury. Discussions of people's own experiences are encouraged. The indirect impact of cognitive difficulties on mood is also acknowledged.

'Personality' pre-/post-injury

The term 'personality' is used as a vehicle for discussion, as in our experience it can be a contentious topic. Conceptually we also view judgments of personality change to be unhelpful to both the client and the clinician (see Yeates *et al.*, 2008, for further discussion). Some individuals feel absolutely no change in what they call 'personality', some state 'I'm still the same person even if certain things have changed' and yet others describe significant change. Asking the question 'What do we mean by the term personality?' is, for some more able groups, an interesting start point. This discussion is roughly divided into three areas.

Development of personality

Following the summary of the previous week, clients are asked what personality is and how they think it forms. Clients are encouraged to reflect on what makes us who we are, and on how our personality is both stable and able to fluctuate and change according to experiences over our lives. The metaphor of how landscapes are shaped slowly over thousands of years by processes such as erosion by the weather is used. Over time a landscape may change in many ways but still be recognizable as the same geographical area. The way in which emotion and behaviour following a brain injury may be shaped by pre-injury personality is raised. The metaphor can be extended by suggesting that the injury is like an earthquake hitting the landscape. Initially there are some recognizable features of the old landscape but these are much less noticeable than the wreckage. Over time the landscape becomes restored, not to its original form, but to a new form where both pre- and post-earthquake features have their own place adding to the character of the view. This point is elaborated through the discussion of how through our lives our personality develops from experiences that shape the 'rules' about ourselves, others and the world around us, and help us to make sense of things that

happen to us, and guide our behaviour. The point is made that our sense of self and identity is always slowly changing, and, brain injury or not, none of us can go back to our 'old' self.

Understanding judgments of personality change

Clients are then invited to consider what they learnt about neurological damage in the previous week, and how this might impact on judgments of personality change, especially by significant others. It is noted how others can see things such as 'being organized', 'having a good memory' or 'being very sociable' as aspects of 'personality'. These things may be changed for a number of reasons post-injury, but the brain injured person would often argue that they are still the same person. How damage to the frontal lobes may impact on judgments of personality change is discussed. The key point to be made here is that judgments of personality change can be made by us and others for a range of reasons, and that this is a different thing from sense of self, or sense of identity.

Effects of pre-injury rules and assumptions on how we cope with traumatic events

Information is presented on how traumatic events may challenge our previous rules for living or personally salient values and goals. We generally discuss how 'rules' are formed by our experiences in life, consistent with the cognitive-behavioural model. For example, many people may believe that the world is generally safe, or that we are in control of our destinies. Traumatic events are generally unexpected and have a large impact on our lives, they can be difficult to make sense of because they challenge our previous rules. The key point here is that some emotional reactions can be understandable in terms of the difficulty of making sense of the injury, especially where certain changes are at odds with the individual's self or personality-related rules and values.

Adjustment to changes and losses

The main aim of this session is for group members to understand their own process of emotional adjustment so far, and to highlight the process of change towards a more positive future. Different types of possible emotional adjustment reaction are described for discussion. These include shock, 'denial', anger, acceptance, sadness or grief, anxiety and hope. We present these as a prompt for individuals to talk about their own process of adjustment to date, and to wonder how much their current emotional challenges may be understandable ways of adjusting.

Situations that highlight differences between someone's life before and after the brain injury may be particularly difficult. The key point for discussion here is understanding the long-term story, with the aim of helping individuals see where they are now as different from where they have been, and that they can expect change in the future. Another key point is that change can involve an increase in negative emotions for many, and to prompt individuals to reflect on experiences in rehabilitation that might be challenging for this reason. Discussion of the kinds of supports people use when coping with the difficulty of adjusting to what's happened is introduced.

Coping style

The aim of this session is to raise awareness of helpful and unhelpful coping styles. Following the summary of the previous week, clients are asked to reflect on how they cope with difficult situations. Helpful and unhelpful coping strategies are discussed. The point is made that following a traumatic event, people may rely on old ways of coping, or develop new ones; cognitive impairments (e.g. to the executive function of problem solving) may mean

that old effective ways of coping are no longer effective or available to someone. Avoidance, use of alcohol or other substances, dependence on others for help, resistance to accepting help, denial of difficulties, worry, rumination and anger are introduced as potentially common responses. Emotional reactions to traumatic events are stressed as normal. However, the point is made that reliance on unhelpful patterns of behaviour may not help us increase our confidence; we may end up developing negative rules and beliefs about ourselves, others and the world around us, which can maintain low confidence, or feelings such as depression or anxiety.

It is suggested that having a wide range of coping styles is helpful possibly due to the wide range of stresses and problems, which occur with brain injury. Helpful styles of coping usually involve problem solving, trying to tackle the problem, trying to develop an understanding of the problem, learning to develop skills to manage difficulties, and seeking and accepting support or advice when needed. Typically, clients discuss their own coping or the person running the group introduces examples to illustrate how a particular type of coping (e.g. avoidance) could be unhelpful in the long run.

Environment and triggers

The main aim of this session is to increase awareness of the impact of the social or practical environment on behaviour and emotions. The topic of how our emotional reactions can be quite specific to certain people, places, or tasks is raised for discussion. If needed, examples of the types of specific challenge created in a situation are given such as the impact of physical and cognitive demands; a trigger for comparison of abilities to prior to the injury; or social or interpersonal demands. The group is encouraged to discuss specific situations that they find more or less difficult post-injury. Examples often include being with large groups of people in social situations, supermarket shopping, certain family or social relationships, noise or other things contributing to cognitive or sensory 'overload'.

Physical and cognitive demands

Discussion of this topic in the group can help facilitate awareness of the environment. This may be due to cognitive problems, physical problems, pain and/or sensitivity to noise or light. So work, home or social environments may pose more difficulties than prior to the brain injury.

Comparison of pre- and post-injury self

Situations may trigger a comparison between pre- and post-injury status. This can lead to being reminded of difficulties, losses or changes. This can be emotionally difficult leading to frustration, aggression, sadness or anxiety in such situations. The group is encouraged to share examples of this type of trigger situation for group discussion, formulation and to identify possible solutions.

Social or interpersonal demands

Common interpersonal difficulties described following brain injury are introduced, such as the difficult balance between feeling helped and overprotected, or being understood as having difficulties at the same time as being trusted and valued. Effects of others' reactions to changes in behaviour and emotions are also discussed as a way of reflecting on how others may change their way of being with us. Clients often have examples of this kind of

trigger situation, and it is sometimes helpful to draw out an interpersonal cycle and open up discussion of what might help break the 'vicious cycle'.

Learning to cope with the demands of specific situations

The emphasis here is that by understanding which situations are difficult and why, it is possible to develop strategies or plans for managing these more effectively. A key point here is that there is variability in emotional and behavioural expression depending on the situation, and understanding what underpins this variation can help with predicting, planning and making changes to avoid inappropriate reactions. Furthermore, global, negative perceptions of oneself, one's abilities, or potential to control behaviour can be challenged by looking at the specific aspects of positive situations and what things influence outcome.

Weeks 6–12: strategies to help manage emotional and behavioural consequences

The vulnerability factors discussed earlier in the group can contribute to a range of emotional or behavioural outcomes or consequences. The group members are asked to brainstorm the emotional and behavioural consequences of acquired brain injury. The list below is then presented and any consequences not mentioned are added to the client's list.

Emotional and behavioural consequences:

- Anxiety, worry and feeling scared
- Negative thoughts
- Awareness
- Anger, irritation and frustration
- Impulsive behaviour
- Social insensitivity
- Sadness, low mood or depression
- Relationship difficulties.

The group is asked to return to the hopes for the group from the first session and depending on the needs of the group, two or more topics are chosen to discuss in detail. Ideas from the previous sessions are drawn upon to help the group try to make sense of the specific topics they are interested in. Sometimes this involves thinking about the organic, adjustment, coping and environmental factors contributing to the area of difficulty. Alternatively, the hot cross bun model (Greenberger and Padesky, 1995) is used to help discuss and unpick an unhelpful cycle of interacting thoughts, feelings, behaviours and responses from others. Finally, the topics are also used to introduce and practise specific mood management strategies, including different types of relaxation strategy, mindfulness meditation, cognitive reappraisal, managing worry (see Butler and Hope, 1995).

The influences of the clinicians running the group can change the focus and strategies identified. However, a core set of cognitive-behavioural principles and techniques are drawn upon. Here we present some background to our approach to some of the common topics covered in the group.

Awareness

With regard to the topic of awareness, the group is introduced to the model of Crosson *et al.* (1989) that identified different types or levels of self-awareness:

1. Intellectual awareness
   - involves having a rational understanding of impairments and the consequences of these
2. Emergent awareness
   - involves noticing and recognizing difficulties as they are occurring
3. Anticipatory awareness
   - involves anticipating that difficulties may arise in the future
   - allows the individual to 'think ahead' and plan to use strategies
   - is the highest level of awareness.

In the group we suggest that awareness may be helped through a range of approaches and invite discussion of the potential effects of these strategies:

- Accurate information about impairments and strengths
- Understanding what can and can't be done
- Asking for clarification from others
- Learning from others what's going wrong and when
- Feedback when problems arise
- Stop–think strategies to improve self-monitoring and decrease impulsivity
- Goal management to anticipate situations, plan, and prepare strategies
- Compensation for the kinds of memory and attention impairments that might prevent someone from having access to new information about themselves
- Systematically learning self-monitoring skills
- 'Behavioural experiments'
- Safe and supportive relationships.

Managing frustration, irritability or anger

We introduce this topic with a discussion of what can lead to anger and aggression. The point is made that sometimes aggressive behaviour can be wrongly described as an expression of anger when it may be a response to threat (as in the fight-or-flight response). Causes of frustration and possible approaches are discussed; often the potential use of cognitive compensatory strategies, to improve effectiveness with a task, or pacing to address fatigue or goal neglect is highlighted. Often arousal reduction techniques are practised in session. When discussing anger the easy to remember strategy (described by Trevor Powell (1994) in the useful Headway guide to head injury) is introduced to the group:

A – anticipate: think about the situation in advance, plan to make it easier

N – notice signs: learn about how anger or frustration affects you, the physical signs such as tension or feeling red in the face, as well as what goes through your mind

G – go through a temper routine: practise some practical things you can do to help calm down. These might include:

- Stop, think!!!
- take a mental step back
- use relaxation/controlled breathing to manage effects of adrenalin
- use cognitive strategies to manage cognitive demands

- talk positively to yourself
- tell the person how you feel (instead of showing them)

Which ones work best for you?

E – extract yourself from the situation: you may need to leave the situation to help calm down. Talking to someone about what happened, doing physical exercise, practising relaxation, or listening to music may all help you to calm down. Pick the ones you feel work best!

R – record how you coped: its easy to forget or not believe you have the skills to manage anger and frustration. Keeping a record of how you coped can help remind you of your progress. This helps build confidence!

Managing anxiety-related problems

The range of different kinds of anxiety problem is described, and the group are asked to focus on one or two specific types of anxiety (e.g. worry, feeling fearful of specific things). Again we note that it is important to understand the factors contributing to the anxiety problem in order to work out the best way of dealing with it. This leads us to work with the group on a specific problem example using the hot cross bun or some other cognitive-behavioural model and moving from this to look at possible strategies or techniques. Again, relaxation or arousal reduction strategies may be practised, or the group may work through the 'worry decision tree' presented by Butler and Hope (1995).

Low mood, sadness or depression

Feelings of low mood, sadness or depression are common following brain injury. If this is an important topic for group members, many find it useful to discuss the ways in which depression can affect thoughts, feelings, behaviour, cognition and physical systems such as hunger, libido and sleep. With our clients preoccupation or rumination seems common, and discussion of the importance of activity scheduling for pleasurable events or tasks that give a sense of mastery is highlighted. We encourage the group to discuss such positive or nourishing activities, and try to link this in with work they may be doing elsewhere on the programme relating to developing an effective memory and planning system. We may also introduce and practise mindfulness as a way of stepping back from troublesome ruminative thoughts. The range of potential strategies discussed includes:

- Planning activities that increase our sense of pleasure and achievement, increasing these a little at a time
- Talking with others who may understand or who have had similar experiences
- Identifying what makes your feelings better and what makes them worse
- Understanding the factors affecting mood
- Recognizing how thoughts, feelings, behaviour and past experiences may be linked
- Recognizing 'negative automatic thoughts' or negative predictions, and seeing how these may affect how we interpret situations
- Coming up with alternative thoughts or predictions with which to challenge negative thoughts
- Learning skills such as assertiveness to help us develop more confidence
- Relaxation to help cope with the stress of beginning to do things differently when confidence is low

- Using cognitive strategies to help improve the outcome of situations or tasks that are difficult due to the cognitive demands
- Reducing rumination and learning to step back from thoughts and feelings (e.g. using mindfulness meditation)
- Antidepressant medication.

Summary

The aim of this chapter was to illustrate the principles and broad content of the Mood Management Group run within the intensive phase of the programme. More information has been covered in this chapter than is possible to cover in 12 hour-long sessions. The information and mode of presentation is adapted to each intake of clients. The programme is always developing further and being subtly changed to meet the needs of different intakes of clients, and updated to reflect recent findings from relevant research, in addition to feedback from clients and our own experiences of what has worked well. However, as yet this cognitive-behaviourally based group intervention has not been evaluated.

Appendix 8.1. Group summary sheet

Date:

Goal area or group:

Session topic or aim:

At the end of the session take time to note:

The KEY POINTS from this session:

My personal 'take home message' for the session:

The next step in developing this:

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Chapter 9

The Psychological Support Group

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The therapeutic milieu in holistic rehabilitation

Holistic rehabilitation aims to create and operate within a therapeutic milieu, a supportive and therapeutic social context that is argued to support the process of change (Goldstein, 1942, 1959; Ben-Yishay, 1996, 2000). Ben-Yishay argues that this social context helps clients develop their sense of identity that they can then take back out into the world and other social contexts such as families, friends and work or college situations. At the Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation, as with other holistic programmes, practices such as a daily community meeting, and an emphasis on group learning, contribute to the therapeutic milieu. In some programmes, the community meeting is used therapeutically as an opportunity for clients to feedback to one another regarding socially inappropriate behaviour, or successful use of coping strategies (e.g. Prigatano, 1999; Daniels-Zide and Ben-Yishay, 2000). At the OZC feedback between and to clients is supported in smaller group sessions such as the Communication Group and other functional groups, as described elsewhere in this volume. On occasion a more general discussion about expectations of one another's behaviour may occur during the community meeting. At the end of the week, the staff and intensive phase clients come together to review the points of learning from the groups and exercises completed over the week. The group is also facilitated to reflect on how they are getting along, give feedback to one another, and identify and reflect on any shared group goals (e.g. being able to get along, communicate and work together as a group).

As a team we have often discussed use of the community meeting for personal feedback and group therapy, as on other holistic programmes. However, we concluded that it just doesn't feel 'right' to be addressing some of these issues in the rather public community meeting as everyone in the Centre, including day visitors, attends it. Perhaps this reflects something about the British cultural context of the Centre.

So feedback on behaviours and strategies can occur within certain specific groups and individual sessions, and discussion of issues affecting the day-to-day running of the Centre occurs well within the community meeting. Monitoring and evaluating the development and maintenance of the milieu occurs in team meetings roughly twice per programme. In this meeting, factors impacting upon the milieu, including the team's emotional response to

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the client group, are formulated and appropriate actions identified. The place for considering group processes and for clients to explore their social identity in interactions with peers is the Psychological Support Group. It is this group that allows clients to draw on and share their own experiences with one another, and which often also provides the setting in which group processes within the milieu can be 'safely' addressed, and clients can reflect on their progress with rehabilitation.

In this section we describe the evolution of our innovative approach, integrating group process models with a cognitive neuropsychological model. This approach establishes a context in which clients work towards the two main goals 'to give and receive support with one another', and if this is not happening 'to work out why and address the problem'.

Psychological support in holistic rehabilitation

The programmes described by Prigatano (1999), Daniels-Zide and Ben-Yishay (2000), Christensen (2000) and others include a group in which relevant topics relating to the stresses of life after brain injury are brought for discussion and mutual support (Klonoff, 1997). Initially a similar approach was adopted at the OZC. The Mood Management and Psychological Support Groups provided opportunities, under guidance and structuring from the clinical psychologist, to identify, discuss and practise strategies for managing emotional consequences of acquired brain injury (ABI). However, within the less structured Psychological Support Group, it became apparent that the dynamic of the group, and the impact of cognitive impairments (especially executive problems) could make the task for the psychologist and client group more difficult. The format of the group evolved and then became formally altered in order to capture the group process, address the influence of executive problems, at the same time as allowing clients to draw on their own significant knowledge and experience in order to support one another. The Mood Management Group became more specifically focused on psychoeducation and strategy development, and is described in Chapter 8. Here we will provide some background to the key literature informing our approach to the Psychological Support Group, and describe the model we have developed for guiding the facilitators working with the group. We will then provide some brief clinical examples and descriptions of specific techniques used within the group.

Background literature

The key group work literature includes descriptions of:

- A group mentality that may reflect the group's shared goal, working together, or a dysfunctional group mentality to respond to perceived threats and anxieties (Bion, 1961),
- Helpful therapeutic activities or 'curative factors' in groups (Yalom, 1975),
- The notion of the group as a single unit, and of processes of formation and development of groups implying initial establishment of the group, negotiation of problems, and engaging in the task of the group (e.g. Schutz, 1958; Tuckman, 1965),
- Foulkes' (1964) ideas regarding the therapeutic task of establishing, developing and deepening of ' "the hypothetical web of communication" that draws on the past, present and future lives of the individual members' (Nitsun, 1996, p. 21) within a group,

- Garland's (1998) notion of the 'adversity group', a type of traumatized group brought together only due to experiencing the same trauma, and related group psychotherapeutic ideas based on Bion (1961) and Foulkes (1964),
- Narrative ideas of how a group's language enables construction of particular stories about the group and its members (to the exclusion of others) which may have a bearing on how the group tackles the challenges of life after brain injury,
- Systemic ideas about working within different levels of context, and exploring culture, beliefs and transitions in relation to the social context within the group and parallels between the group processes and wider systems such as family, healthcare systems or society as a whole.

The notion of the therapeutic milieu as described by Goldstein (1959) and elaborated on in holistic neuropsychological rehabilitation by Ben-Yishay (1996, 2000) is also drawn upon. This provides a model for thinking about the way in which the group contributes to development of social group skills, and coherent sense of identity, minimizing the 'catastrophic reaction' and fostering self-acceptance through the safety of the milieu. The same principle of 'generalization' from the milieu to other social groups described by Ben-Yishay, as mentioned above, is considered relevant to the Psychological Support Group.

Therapeutic work with clients affected by ABI needs to take into account the pattern of strengths and weaknesses in cognitive and social skills. The most common family of deficits faced by clients at the OZC are executive skills, so the cognitive neuropsychological literature is helpful in making sense of and running the groups. There is a range of models and problems associated with the dysexecutive syndrome that we will not go into here. However, we can say that the models of Luria (1966), Duncan (1986), Sohlberg *et al.* (1990) and Shallice and Burgess (1991) are especially helpful. These models emphasize the ability to identify a goal and generate a plan, keep a goal and plan in mind whilst working towards it, and self-monitor in order to adjust behaviour. Metacognitive abilities, abstraction, regulation of affect, behaviour, social skills, and capacity to self-reflect and so learn to develop and update self-representations are major challenges faced by those with dysexecutive syndrome. Within groups then, clients may fail to stick to task or topic, be tangential in their speech, miss important social cues (e.g. misinterpreting humour, not picking up that another is upset), or have stronger or weaker emotional reactions than might be usual. Vygotsky's (1960/1978) notion of how higher cognitive functions emerge as 'mediated processes' from the interplay between the social and the organic allows us to think about how social context, interaction and the tools or symbols of language may be internalized to form self-regulating capacity. This notion is echoed in contemporary ideas about rehabilitation of executive function and psychological therapy (e.g. self-instructional training, Meichenbaum and Goodman, 1971; Alderman and Burgess, 1990; Cicerone, 2002). These ideas are brought to life in the Psychological Support Group in defining the role of the facilitators as serving 'executive', 'supervisory attentional' or 'metacognitive' functions. By defining the ongoing 'main goal' of the group as 'to give and receive support with one another', and the 'second goal' 'to notice if this isn't happening and do something about it', the group is provided with a necessary focus for social problem solving together. Given the challenge of this for the clients, the facilitators' roles become clarified:

- define and remind the group of its goal(s)
- reflect on progress towards the goal(s)

- provide explicit feedback and reflections on activity, feelings, and themes in discussions in the group
- highlight activities in the group that may go against or distract from the goal
- support problem solving through promoting divergent thinking
- be the 'autobiographical memory' for the group, reflecting on any changes in the group, examples of past problem solving or significant group events, and creating a sense of continuity and coherence
- prompt the group to think about the future in relation to the specific goals of the group, changes that occur in the group, and generalization of learning from this group to others
- support the group to develop the conditions necessary for these processes to occur (e.g. supporting group development and cohesion if necessary).

How are emotional issues or group process issues managed in this format? This description of executive functioning at the group level to some extent is seen as consistent with Bion's (1961) model of group process. Bion suggested that groups can operate in either a healthy, 'work group mentality' or unhelpful 'basic assumption mentality'. In short, Bion suggests the latter category can be recognized by attempts of the group to move away from the task, place responsibility with a specific group member, or operate to encourage union between two group members. It is also suggested that it is the response to anxieties within the group, or attempts to avoid some feared topic or aspect of working together, which leads to movement away from the main task of the group. So the presence of a difficult or distressing topic or issue may lead the group to spend time talking about mundane issues, fall into silence, or attempt to engage the facilitators in discussion about their lives to avoid potentially unpleasant affect, to name but a few possibilities. The language of the facilitators addresses the group as a single 'responsible entity', to highlight the notion that the group can self-reflect and manage its own behaviour, and has some responsibility for working towards the main goals. For example, a facilitator may reflect at a relevant point: 'it seems that the *group* has *chosen* to talk about the weather today – I'm wondering how this fits with the group's goal?' This can prompt the group to engage in discussions about what was decided when, and therefore help the group to then work together to make a choice about what to discuss in the group. Implicit in this is the idea that group members are responsible to an extent for one another's capacity to benefit from the group. At times, the contributions of individuals may be emphasized or highlighted by a facilitator, in relation to the group's job of working towards one of its goals. An example of this might be a reflection from the facilitator that 'the group has been working well towards its main goal today, and we've heard a number of suggestions to support Bill with stresses at home – I'm also aware that there is a member of the group who we haven't heard from at all today'.

Thus with a therapeutic sleight of hand, the facilitators can be reflecting on group processes in relation to the emotional life and function of the group whilst also demonstrating the 'executive function' for the group. Through reflecting conversations between the facilitators, it is possible to comment on the discussion and feelings within the group. Highlighting what is going well or introducing new ideas in a non-confrontational manner through these conversations can help the group to understand their experience in the group and open up new possibilities or ideas for discussion. This facilitates the potential for the group to support one another, and at the same time 'compensates' for the group's dysexecutive difficulties. It is this simple principle that forms the cornerstone of the group,

in addition to which facilitators may draw more or less on other schools of therapy and group work, as noted above. The overall message of the group is 'despite your injury you have a lot to offer other people, you can be a friend, colleague, source of support to others, your pre- and post-injury life and experiences are valid and appreciated'. When the group is most successful, clients realize this slowly but surely and towards the end, often make reflections with a theme of 'becoming a person' again. This is usually not without difficulties, tensions, or problems arising within and for the group.

A description of the Psychological Support Group

Group membership

The Psychological Support Group is the only group that runs throughout the six months of the programme, involving clients in both the intensive and integration phases of rehabilitation. There is a rolling pattern of change every three months with part of the group leaving, part of the group moving from 'newcomers' to 'old hands', and a new intake joining. The group is typically no larger than eight to ten clients, with two facilitators. Exclusion criteria are the same as for the programme as a whole, ensuring inclusion of all clients. It is worth noting that on two or three occasions over the past five years of the group, a group member has chosen to, or been asked to, leave the group. In one case this was due to verbally aggressive behaviour in the context of receptive and expressive communication difficulties and deficits in emotion recognition. A second case related to a client who was depressed, struggled to participate in the group and was finding work on other aspects of the programme challenging. So with the support of his individual programme co-ordinator (IPC) the decision was made with him to drop the group to focus on other priorities in his programme. In these cases the client was supported to share their decision with the group before leaving. It has also been the case that a client may share the decision to leave the group and then go on to stay. One client felt concerned about his post-traumatic stress disorder (PTSD) symptoms and had not discussed this with the group. After sharing the decision to leave and his related feelings about his PTSD symptoms, the client discovered another group member had similar symptoms, and the group were able to discuss how best to respond to their needs, and the client decided to continue with the group.

Clients with significant communication problems, or more severe behavioural disturbance such as aggression, which they are unable to control in the rehab setting, should be excluded, as the group may be unhelpful to both the individual and the rest of the group. Having said this, clients with less disruptive but nevertheless problematic behaviour may benefit from feedback from the group, and being expected to take responsibility for giving support in the group. When the whole group is made up of more severely memory-impaired clients, alternative strategies may be required in the group. Clients can be supported to provide immediate support to one another in the group, but the facilitator may need to be more proactive in suggesting strategies, e.g. note taking, chairing, recapping from last week, or setting topics for discussion. On one occasion, in a group of four memory-impaired clients and one client with emotional and executive difficulties, after the first few weeks of rather empty discussions about holidays, past work roles and general chat, the client with executive problems became irritated. She angrily stopped the group and pointed out that they were wasting a potentially useful hour of rehab time and what could they do about it. This prompted the group to realize that they did not know or recall much

about one another and over the next few sessions devised games for getting to know one another. This culminated in clients bringing in personal memorabilia to share something of their identity with other group members. A mix of clients with memory and other problems can work better, but at times an individual client may still require external support (for example in communication, mood, cognitive or IPC sessions) to think about using strategies in the group. The group has been used as the context for 'behavioural experiments' being carried out by individual clients working on communication, cognitive strategies or finding out if their own view of themselves matches that of others.

Administration of the group

This is heavy clinical work for the facilitators, so taking time after the group to discuss together what happened and how you responded to the group is useful. At times, we have made use of the other sources of support built into the programme. For example we may share the key issues from the group with colleagues at the 'business of the day' meeting at the end of the day. Documentation for the group is kept as a single continuous record, written by one of the facilitators after each group, taking it in turns to balance the workload. The approach to note writing is to describe the activity of the group, and to hold back from making additional interpretations other than describing the reflections made within the group. If the group needs something to be carried over or there are other plans of action (for example, facilitators providing a written summary of the group rules) these too are noted. At the end of the notes, comments about post-group reflections of the facilitators are added as a developing formulation of group process.

The first group

At the start of the first group the facilitators' job is to set the scene, define the goals and support the group in getting to know one another and sharing experiences. The degree to which facilitators step back to allow the group to find its own way, or be more proactive in engaging or suggesting icebreakers depends on the make-up of the group and their strengths, weaknesses and skills. Within the programme, the facilitators are explicit about describing this group as different from other groups in the programme:

> The other groups are about being given information, new strategies or to relearn or develop skills. We know that as a staff team we can't know everything about brain injury. Especially we don't know what it is actually like, we have not experienced it directly. This group is a chance for you all to share and benefit from one another's expertise and experience of brain injury. We are here to support you in this, to help you make the most of this opportunity, and help solve problems if need be. But mostly it is down to you what you do and how you do it. All you have to do is keep the main goals of the group in mind. The first goal is 'give and receive support with one another', and the second is 'to notice if this isn't happening and work out what to do about it'.

We explicitly state that this is a harder task than it at first seems, and the group may not make sense over the first few weeks. Examples of the kinds of things previous groups have done are also shared.

> This group is actually harder than it seems. But we are here to support you. We have also done this work with lots of other groups. Some groups have used this as a chance to bring in and play CDs of music or show photos or videos that are important to them; others have played games in the group to help get to know one another, some have

taken a very structured approach to discussions and others have been less structured. It's up to you to find things that are helpful. Just remember the main goal is about giving and receiving support, and the second goal working out the best way to do this.

Facilitators and group members will also describe the rules of the group. There are some non-negotiable rules:

- only one person speaks at a time
- what is discussed in the group is confidential
- visitors and assessment clients do not join the group
- clients must show respect to one another in the language they use
- behaviour or language which disrupts the group on more than three occasions and remains not addressed by the group or the client is not accepted and may lead to the group member leaving the group.

Rules may be written and circulated, or prompted verbally, again according to the needs and preferences of the group. Group members may add their own rules or ways of running the group, and share these with newcomers in the first group. Such rules or practices may well be renegotiated as the group changes. A repeating approach to the group has been to start the group each week with a 'round' of the group, to hear from each member. Sometimes this is left open, and sometimes this has been defined. For example several groups have found 'good news, bad news' or 'highs and lows' useful, where each member reports one good and one bad thing from the past week. However, other groups have resisted the structure of this, with varying degrees of success. Some have suggested topics of mutual interest for discussion, or identified topics from the current group discussion to spend more time on in a following group, thus providing the flexibility of allowing significant issues to emerge, but with the option of structure being used when important issues come up.

When there is a new intake into the group, the previous intensive phase clients will also welcome the newcomers. Typically they are encouraged to think about how they might do this some weeks in advance of the new intake starting. Sometimes the group is curious about the newcomers and initiate planning the 'induction' of newcomers themselves. What the clients say depends very much on the group, so it is hard to describe anything specific here, but we can try to give an impression by describing some general and specific examples.

The most common first group icebreaker has been for each group member to tell his/her 'story'. This has often provided a good means of clients identifying similarities with one another, stimulating discussion about a range of topics such as injuries, hospitals, past rehabilitation, support and understanding from others, medico-legal processes, impact on family members, driving and welfare benefits. Yalom (1975) has identified one of the curative factors in groups to be this activity of sharing and identifying commonalties. On occasion, group members have chosen to avoid this type of self-disclosure early in the group, saying that it might be too much for the newcomers. Group members may decide to wait until the newcomers start and ask them what they might find helpful. If the group is stuck planning for newcomers, the role of the facilitators is to support social problem solving. This is typically done by encouraging the group to reflect on their experience of starting in the group. From thinking about what they might have liked, and what they did and did not appreciate in their own first session, group members can be supported to generate examples of possible ways of welcoming newcomers or structuring the first session. If the group makes a plan then forgets to implement it when the newcomers join, the facilitators' role is to note that they have decided not to follow their plan and to remind the group of what they discussed previously.

The group has at times used the first group as a chance to share their experiences of the first part of the programme, giving tips, making supportive comments, or talking about transport, accommodation or other practical issues. The group has also at times focused on the Psychological Support Group itself, saying how it's hard to explain at the start, you just have to do it to know what it's about. Often clients say that at first it just seems confusing and it is not clear how it is helping, but that over time the group finds its feet and becomes a useful source of support. On occasion clients reflect on how their role or experience in the group changes when influential group members leave. One client commented in the first group after a change that another group member who had just left had been like the father figure to the group, and now he felt that expectation on himself. Another group anticipated how one group member leaving would impact on them. In this discussion they talked about how she served the purpose of keeping the group in line, and the notion of an 'anchor' was used. A group member drew an anchor on the whiteboard in the group room to serve as a reminder to the group to help them stay joined together, whilst also recognizing their differences and relative independence. In the first group with the newcomers, the established group members were able to explain what they had experienced in the group and how this 'anchor' was a reminder to them of the 'missing' group member who had helped keep the group in line. A final example involved an old hand's comments about his adjustment. He said to a group of newcomers that, from their initial chat in the group, everything in their lives is brain injury, everything they think and talk about is brain injury, as if it's a high brick wall they're standing right in front of so they can't see or think about anything else. He said that, like he is beginning to do, they have to break through 'the wall' so brain injury is just a part of their lives, not the be all and end all. This client drew a brick wall on the whiteboard and drew on arrows, talking through his adjustment process as trying to punch through the wall. One of the new clients commented that his knuckles are bruised from trying. The motif of the 'wall' remained in the group explicitly on the whiteboard and was also referred to at times by group members and facilitators reflecting on adjustment and progress in rehab.

Up and running: facilitating subsequent sessions

The most important thing in subsequent sessions is for the facilitators to remember the two main goals of the group. Holding these in mind whilst listening to the group's discussion helps focus on what the group are doing. The kinds of things we try to bear in mind are:

1. Are they being supportive with one another, or working on how to be supportive?
2. How are they doing this? (thinking about Yalom's (1975) 'curative factors', Bions' (1961) 'mentalities', Foulkes' (1964) systemic ideas about sharing, deepening and reflecting communication, and considering the dominant and subjugated narratives (White and Epston, 1990) and communication, cognitive and social skills).
3. What helpful or perhaps not so helpful things are group members doing?
4. What are the general themes emerging from the discussion?
    - What problems or issues relevant to brain injury and rehab are being discussed?
    - How might these relate to the group right now, and any processes within the group?
    - How might themes relate to the broader task of adjustment and acceptance post-injury, or where the clients are up to in their rehab, or processes in the therapeutic milieu?

5. How does the group 'feel' – for example is the pace slow, laboured and downbeat, or lively, chatty and tangential, and what might this mean?
6. What group processes are occurring? (again thinking about Bion's model, or systemic ideas).

Events in the group can then be organized under these general headings. There are far too many examples for us to provide here. However, the following descriptions may help provide a sense of what we think fits within this structure. The first three items in this list bear direct relevance to the writings of Yalom (1975) on curative factors in groups. These include:

- Instillation of hope
- Universality (seeing that one is not alone with one's struggles)
- Imparting information and sharing knowledge
- Altruism (unselfish giving of support)
- Development of socializing techniques
- Imitative behaviour
- Interpersonal learning
- Group cohesiveness
- Catharsis – expression of pent-up feelings.

These provide nice headings that can be used to further categorize activity in the group and be reflected back to the group at a relevant time within the session.

'Today the group has been sharing its experiences and finding out about how they are similar in many ways'.

'Bill talked movingly about his loss of work role, and other group members shared their similar experiences …'

'Pete told Bill and Jane about how he has been discussing work options with a vocational advisor, and suggested a contact to pursue'

'The group has talked about feeling judged by society as "damaged goods" but that in some situations their real difficulties are not recognized, and have vented some anger about this frustrating dilemma'

At the same time as noting the possibly supportive activity of the group, feedback on how the group has stayed on task can be given. This may be either during the group (more likely if they are going 'off task'), or at the end, in summary of the session.

> The group has worked really hard today on some difficult topics. Group members have been using their own knowledge and skills to support Bill and Jane, who had worries about rehab and getting back to work. The group has stuck to the task of giving and receiving support.

We may need to offer reflection regarding the groups' work on goal 2, i.e. making an attempt to be more effective with regard to goal 1. This might be something like:

> This week the group chose to structure the group by going round to make sure everyone got a turn to speak. Does the group think this has been a helpful strategy for the goal of the group, which is to give and receive support with one another? How does this compare with last week's session, which was not structured?

As mentioned earlier, the facilitators may need to act as the autobiographical memory for the group, and support problem solving if the group is stuck. This can involve 'handing down' experiences from previous groups.

> in a previous group they felt that there was an expectation they had to talk about emotionally 'heavy' things. This made it hard for them to get started, so they decided to start the group each week with each client saying something good and something bad from the past week. They said this could be personal or something from the news, or music or anything you might want to bring. I wonder if this might be helpful for the group today?

The themes that seem to emerge from discussions that initially seem removed from the typical concerns of life after brain injury can be fascinating, surprising, personally significant or often strikingly relevant to adjustment post-injury or the process of rehab. The typical approach taken by the facilitators is to allow the group to get under way, and after a period of time offer a reflection on any possible themes as they emerge. It is hard to say how long to wait before making a reflection on a theme, but in general this can be between 15 and 30 minutes, or after a 'round' of hearing from each group member if the group has adopted this strategy. The facilitators' reflections on themes are seen as ways of raising possibly relevant topics, stimulating self-reflection, encouraging supportive conversations or conversations about the process of the group, and reminding the group of its goals. There is an element of active construction here. In listening, the facilitators' work is to pick out themes in stories or discussions that reflect on life after brain injury, or on the hypothesized processes within the group. It can be helpful to positively reframe conversations (Vetere and Dallos, 2005), in terms of identifying positive motivations, care or concern expressed within the group's conversation. Reframing offers clients the possibility of alternative perspectives and redefinition of problems, and creates opportunities for holding a new position in relation to others. A general example might be group members talking about travel, hassles with managing transport, being unable to drive, relying on others and fatigue. This type of discussion could be reflected on directly, as in the examples above. However, if the facilitators are aware, or the group has previously referred to the challenges of adjustment, an alternative tentative reflection could be made.

> I'm just wondering how all the hassles and struggles the group is describing about transport and travel also fit for adjustment after brain injury. Things not going as planned, being let down, not getting where you want to be, getting lost, letting others down, getting tired. I'm wondering if that's how the group is feeling today?

The following example shows how adjustment issues emerged from an apparent conversation about current affairs. In a group session not long after the events of 11 September 2001, the group began discussing terrorism and its impact. The facilitators did not offer any initial reflections and the group continued with the topic. One of the group members raised the issue of what to do about the loss of the World Trade Center and potential redevelopment of 'ground zero'. There had been a television programme on this topic, and discussion in recent news programmes. The group reflected on the relative merits of trying to restore the Twin Towers exactly as they had been, just leaving the site as it was, clearing up and leaving a memorial, or building something new. As the conversation continued the parallels with the question of how to adjust to life post-injury (write off the past, try to rebuild it exactly as it was, or what …?) became apparent. At a natural break in the discussion the facilitators reflected on this, asking the group if the issue of how to address

this enormous loss fitted with their own adjustment stories. The group continued their discussion, this time talking movingly about their own attempts to adjust, 'rebuild' and accept changes and losses. Conclusions were drawn about the inappropriateness of trying to rebuild things exactly as they were, the need to recognize and respect the past and not to forget, but to move on.

Often the group engages in more practical support, typically exchanging information about medico-legal case processes, driving assessments, medication, welfare benefits, additional sources of support. At times the facilitators may be asked for information, this is given if appropriate to the task of the group at that time, and if they have the knowledge. Otherwise the group is directed to other sources of information outside the group session, or specific questions may be followed up after the session with the client and their IPC.

A further type of reflection involves noting the 'atmosphere' in the group – did the group session feel happy, reflective, emotionally hard etc. At this point, a reflecting conversation between the facilitators, in front of the group, can be helpful. We otherwise offer this tentatively, as if counselling an individual, and we invite the group to comment on their own experience of the group and on the reflections of the facilitators. This may or may not lead to further discussion, and sometimes it seems enough that the feeling of the group is noted. Again, this form of reflection can be thought of as emotionally supportive or validating activity, as well as an executive self-monitoring or metacognitive activity.

In our experience the group is powerful and often difficult. Having two facilitators helps for peer supervision and reflection. When reflecting on group processes, Bion's (1961) ideas about 'basic assumption mentalities', and systemic ideas about construction of meaning through language, dominant and marginalized narratives, and the role of reflection in groups, are drawn upon. Reflections based on Bion's ideas tend not to explicitly or rigidly refer to his definitions of basic assumption mentalities. Rather, if a tendency for the group to defer responsibility to a 'leader', or 'run away' from a difficult topic arises this is commented on more concretely.

'I'm aware that a few moments ago Bill brought up that he is having an especially difficult time at home right now. The group did not seem to respond to this but moved on to another topic.'

'The group took some time to get under way today. There was lots of "banter" and it was hard to work out what the group was doing. Jane seemed to be the one that called the group to order.'

These reflections are aimed not to be critical, but to allow the group to have a discussion about what is happening or has happened in the group. In this way 'processes' can be made explicit. In response to the previous examples the group might 'decide' together that they need to rely on prompting from the facilitators if they have not noticed or replied to a group member, or that it is best if Jane take charge to help the group get started. In future groups the facilitators may ask if their role of prompting is still required, or ask if the approach of Jane as 'leader' is still working or helpful.

Returning to Vygotsky's (1960/1978) ideas about mediated processes, it is hoped that, through the intermittent presence of reflective comments from the facilitators, supportive comments from peers, or social problem-solving discussions with both peers and facilitators, the group members begin to internalize these voices. Occasionally this is seen occurring during the development of the group, as one or two group members begin to

actively reflect with the group on the two main goals, or note process issues like a group member being 'left out' from the discussion, adopting a similar style to that used by the facilitators.

Ending groups and transitions

The group has a rolling membership so in itself does not end. However, obviously a group of clients will come to the point of leaving the group when ending the programme. This point coincides with a process of change for previous newcomers who move into a different phase of the programme, and the arrival of a new intake of clients. The practicalities of how to welcome newcomers are addressed as described in the 'first group' section above. Issues relating to ending rehab, leaving the group and starting or developing new activities and roles are therefore mixed with other issues for the group. This process of change or evolution within the group is frequently met with anxiety and uncertainty, either explicitly identified by at least some group members, or suggested by increasing attempts of the group to avoid the main goals, or perhaps becoming increasingly disorganized after a period of effective group work. Typically, the facilitators may need to identify and label a range of possible reactions or mixed feelings. From after about week 6 of the 12-week cycle, we try to listen out for talk of change, uncertainty about the future or next stage of rehab, or other themes of uncertainty. If it seems appropriate reflections on this may be made.

> The group have been talking about different social groups they've been in, and how these have changed since their injury and again through being in rehab. This seems an important topic. But I am also aware that this group will change in a few weeks. Some of you will be leaving, some progressing to the next stage, and new people will join the group.

This reflection sometimes prompts practical discussions about who will be coming and when, how those who are leaving plan to stay in touch, how big or small the group will become, whether the seating is comfortable or whether the group should be renamed. Often the group also reflects on other groups they have left behind, returning to family or work roles and social groups. Sadness at leaving, but hope for the future is often brought up. On occasion, transitions in the group may trigger memories of other significant losses or a transition perhaps predating the injury. This may be especially so towards the end of the group since leaving the group coincides with finishing the rehabilitation programme. Meanings of loss or change may be considered in terms of meanings developed through stories told about past losses or transitions, and through which we ascribe meanings to the present and the future (White and Epston, 1990).

Within the models of Yalom (1975), Foulkes (1964) and Bion (1961), such processes may become played out in the group so an individual may be anticipating or experiencing unbearable negative affect in themselves or painful rejecting behaviour from others. In responding to this, the individual's behaviour will impact upon the group, and it is understandable for someone feeling this way to attempt to engage the group in discussions or activity that minimizes any feared outcomes or associated distress. Within the Psychological Support Group, the occurrence of transitions within the group prior to individuals leaving the programme helps provide information about how group members and the group as a whole may respond. The facilitator's role of anticipating upcoming transitions is important for problem solving in the present. If the facilitators formulate the group

as engaging in processes that take away from a goal of planning for the newcomers or managing other aspects of transition because of past painful losses, they may make reflections that highlight the possible activation of past memories of loss or transition and move towards problem solving.

> Today the group set out to discuss the changes that will happen in the group soon, new people arriving and established people leaving. It seems like this has been difficult, the group discussion has jumped around a lot. Transitions like this are difficult for many people, regardless of brain injury. Between us we have experienced a lot of losses and transitions, like leaving home, relationships ending and bereavements. I'm wondering what ideas the group has from past experiences that might help with the current task of the group.

Such reflections provide a means of helping clients explicitly label their experience of ending rehabilitation or leaving the group as equivalent to leaving school or college, or completing a course. One client described her experience of the programme to a newcomer as like 'going to college to do a course in your "self"'. The analogy of driving lessons has also been raised, the idea being that rehab provides the basic foundation ('passing the driving test') from which the clients develop and apply their skills post-rehab ('the many routes to be driven, trips to be taken'). When a client has explicitly described feeling distressed by the ending, and is perhaps making negative predictions post-programme of social isolation or returning to pre-rehabilitation life, the group's goal is no different, to be supportive to one another through this. However, in the context of the group ending, the issue of who provides such support post-programme may also be raised. Group members often discuss their family, social or other support networks, skills and strategies learnt through rehab, hope for the future in relation to new work, study or social opportunities, and also remind one another that they plan to stay in touch, and check they have one another's contact details. The group may remind one another, or be reminded of the ex-clients' forum (see Chapter 22).

In this way the group process demonstrates processes broadly similar to the stages traditionally recognized in the group work literature (Tuckman, 1965):

- the development of group cohesion through sharing stories, clarifying the task of the group, negotiating and clarifying roles
- tackling problems and social problem solving with others, discovering differences, disagreeing and resolving disagreements
- applying skills and knowledge, and developing roles to achieve the primary task of the group, and therapeutic activities such as catharsis and active seeking of help and support
- consideration of the future and plan for generalization of such skills and experiences to groups away from the rehabilitation programme.

Continuity of contact with peers from the programme is an important part of clients' experience of the programme, and recently the formation of a service user group for the Centre has provided a more formal means for clients to maintain contact with one another (see Chapter 22).

Summary

This innovative model of group work in neuropsychological rehabilitation carries the face validity of combining group process and cognitive neuropsychological approaches. In

the experience of facilitators and from feedback and comments from clients, it appears to have an important role within the holistic programme in terms of facilitating adjustment, practising skills, having a valued social role with peers, and for issues in the therapeutic milieu to be identified or addressed. It is perhaps the most challenging group, and this can make it an especially potent trigger for some clients. It is possible that there are many individuals affected by brain injury for whom this group would be too demanding. Furthermore, a group of this type has not been evaluated so we don't know if it is effective on its own outside of a rehab programme. It clearly does offer something to our rehab clients, which they would not get from their other sessions here. We end this chapter with some comments made by one group in their final session.

Group members reflecting on the group

'over a period of time you become aware other people were suffering the same issues I was suffering from'

'if you haven't got the answer someone else in the group may have one you can take'

'the group's helpful because … although everyone's problems are different its amazing how many parallels can be drawn'

'it doesn't take the problems away or make them easier but does make it easier to know that you're not going through things alone … its not such a "me, me, me!" problem'

'you realize your problem wasn't quite as bad as what you thought'

'we got to know one another, got more comfortable … if you don't want to say something, you don't have to'

'every week we get the opportunity to talk about things that've happened that are good, and things that've happened that are bad'

'to the average person it wouldn't mean much but in here (the group) you can share that, get excited about it, "I did really well", "good for you" … in everyday life people might not see those things'

'it turns out that problems you think are due to brain injury might just be everyday problems'

'through the group I got a better understanding of what was my brain injury'

'in individual sessions you can feel the spotlight … in here its focused on the group, not on any individual … that judgement just isn't there'

'with brain injury sometimes you feel people are looking for problems … in the group people don't even try to understand they just accept and seem easy going rather than trying to pinpoint problems … there's a real feeling of acceptance'

'and it allows you to questions things … may be this is a problem I have'

'we've been faced with having to agree to disagree … learning to be able to sit back and see other peoples' points of view … you might be defensive about it and not want to take someone's angle … once you step back and can see it from a different angle then …'

'making sure everyone had the chance to talk, be involved, rather than ignoring anybody or focusing too much on someone … we kept an eye on one another'

'I took the back seat because I was the one who usually started the conversations … because I wasn't talking people made the mistake of bypassing me … we made sure it didn't happen the following week … we became aware its not fair to bypass someone … we came up with a strategy pay attention in the group and ask one another'

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Chapter 10

Working with families in neuropsychological rehabilitation

Giles Yeates

Introduction

When you read the title of this chapter, who might you have in mind as the subject of the text? Who might be included in your idea of 'family' … spouses, non-married partners, parents, siblings, or children? Could the person with acquired brain injury (ABI) be in your family? Would you be expecting them to be involved in all family conversations or for there to be some separation of individual neuro-rehabilitation and relatives-focused intervention? Finally, for whom do you delineate your service provision boundaries within your core remit as a neuropsychological rehabilitation service, be this in an ideal situation or in reality?

Questions of this type have influenced the development of a particular perspective in family work, and the development of systematic involvement of families and carers as a core component of the Oliver Zangwill Centre (OZC) neuropsychological rehabilitation programme (see Appendix 10.1). Work with professional carers who are not family members is not a focus of this chapter, although many of the ideas discussed will have some relevance for such work. An aim central to this chapter's perspective is the facilitation of helpful *conversations* between configurations of family members and those connected with them, organized in particular relationships following ABI (including relatives, the person with ABI, and of course services).

A context is established for this approach through a brief summary of the dominant family needs following ABI, prioritizing family work in neuropsychological rehabilitation. This is then followed by reflection on complexities in the relationships concerned. A theoretical and epistemological perspective is then outlined based on an integration of ideas from systemic family therapy and neuropsychology. It is proposed that this perspective is well placed to respond to family needs and complexities, and is also applicable to all aspects of family and carer work. Finally, this theoretical basis is illustrated through specific suggestions for intervention within the broader course of rehabilitation. The specific procedures used for involvement of family members and for provision of the relatives' groups at the OZC are not considered in detail, although outlines are provided in Tables 10.1 and 10.2, and an extract of our procedure for involving families and carers is included in Appendix 10.1.

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Family needs following ABI

The literature on psychosocial outcomes following ABI has repeatedly highlighted a picture of critical and diverse needs of relatives. Both longitudinal outcome and cross-sectional studies have demonstrated in family members increased levels of low mood (Rosenbaum and Najenson, 1976; Gillen *et al.*, 1998), strain/stress or burden (e.g. Bond *et al.*, 1979; Brooks *et al.*, 1987; Mazaux *et al.*, 1997) and clinical levels of psychological distress (e.g. Kreutzer *et al.*, 1994; Perlesz *et al.*, 2000). In tandem with these studies, several authors have identified common outcomes for both relatives and the people with ABI themselves, such as challenges to psychological and marital adjustment (Blais and Boisvert, 2005), sexual and relationship difficulties (e.g. Gosling and Oddy, 1999; Oddy, 2001; Ponsford, 2003) and marital strain and breakdown (e.g. Peters *et al.*, 1990; Moore *et al.*, 1993; Kreutzer *et al.*, 1994, 2007; Wood and Yurdakul, 1997; Gosling and Oddy, 1999). An additional common outcome is social isolation for both the person with ABI and their relatives (Elsass and Kinsella, 1987; Kinsella *et al.*, 1989), which has been shown to increase over time (Bond *et al.*, 1979; Brooks, *et al.*, 1987). Finally, one further shared difficulty experienced by both people with ABI and relatives is a problem with sense-making, accessing information and understanding (Sinnakaruppan and Williams, 2001; Yeates *et al.*, 2007).

Complexity and diversity in families, carers and services

Concurrent with the identification of these needs in psychosocial outcome research, issues of complexity and diversity have been raised when families are experiencing and identifying difficulties. Some studies suggest that the relationships between ABI sequelae and family outcomes are not linear, but in fact mediated by a number of psychosocial family dimensions. For example caregiver distress and burden may be mediated by perceived social support (Leach *et al.*, 1994; Ergh *et al.*, 2002, 2003).

Furthermore, a review of the outcome literature identified a constellation of psychosocial predictors of couples' outcome following ABI (Perlesz *et al.*, 1999), including age (Vanderploeg *et al.*, 2003; Kreutzer *et al.*, 2007); gender (Gervasio and Kreutzer, 1997); culture (Vanderploeg *et al.*, 2003) and duration of relationship pre-injury (Wood and Yurdakul, 1997; Kreutzer *et al.*, 2007). Additional predictors include the presence of mental health difficulties in the relationship pre-injury; work status of the ABI survivor (Vanderpoeg *et al.*, 2003); presence of children in the family (Thomsen, 1984); financial difficulties (Peters *et al.*, 1990; Moore *et al.*, 1993; Hall *et al.*, 1994) decreased marital cohesion and increased conflict (Maitz, 1990, 1991); loss of a peer-based, supportive relationship (Panting and Merry, 1972; Kreutzer *et al.*, 1994) and role changes (Rosenbaum and Najenson, 1976; Thomsen, 1984; Henry *et al.*, 1985), notably if the person with brain injury was a father pre-injury (Peters *et al.*, 1990; Moore *et al.*, 1993).

Elsewhere in the ABI literature, the conceptualization of circular relationships between family variables has become increasingly prominent. Studies focusing on childhood ABI have used sophisticated designs and statistical procedures to empirically demonstrate reciprocal causal influences within families post-injury (e.g. Taylor *et al.*, 2001). Within the literature on ABI in adults, publications mapping specific, non-linear and cumulative influences within families are growing in number (Thomsen, 1974; Carnwath and Johnson, 1987; Krefting, 1990; Moore *et al.*, 1993; Pessar *et al.*, 1993; Johnson and McCown, 1997; Flanagan, 1998; Sander *et al.*, 2002; Yeates *et al.*, 2007).

If one dimension of complexity is the cumulative interrelationship of family members and family variables, then a further dimension is that of family difference. Broad dimensions of difference across families highlighted by researchers include diversity in culture (Horan, 1987; Cavallo and Saucedo, 1995; Johnson and McCown, 1997) and socio-economic background (Smart and Smart, 1992). Other studies have highlighted diversity in experienced difficulties within families. Some studies have found parents of adult ABI survivors to report different levels or time-courses of stress, strain or burden than that reported by spouses (Panting and Merry, 1972; Thomsen, 1974, 1984; Rosenbaum and Najenson, 1976; Krefting, 1989; Hall *et al.*, 1994; Kreutzer *et al.*, 1994; Gervasio and Kreutzer, 1997). Other studies have identified unique responses of siblings (Orsillo *et al.*, 1993; Pessar *et al.*, 1993; Perlesz *et al.*, 2000) and male relatives of female survivors of ABI (Kay and Cavallo, 1994; Gervasio and Kreutzer, 1997; Gosling and Oddy, 1999; Perlesz *et al.*, 1999).

Considered by many authors to be a family subgroup that have been neglected most disproportionately to their own needs, child relatives have been identified as experiencing a range of shared and unique emotional and behavioural difficulties following the injury of a parent (e.g. Pessar *et al.*, 1993; Urbach *et al.*, 1994; Butera-Prinzi and Perlesz, 2004). Studies highlight a multi-factorial and relational context around the adjustment of child relatives. Authors have found the gender of the injured parent to be predictive of child-focused outcomes, in addition to circular, reciprocal influential relationships between the parenting style of both injured and non-injured parents, depression in the non-injured parent and emotional and behavioural problems in the children (Pessar *et al.*, 1993).

Finally, negative psychosocial outcomes for families following ABI are not universal inevitabilities, and perhaps are in part reflective of the problem-focus of the dominant trends in research enquiry. In contrast, some authors recognize positive outcomes and key competencies in some families following ABI (Kravetz *et al.*, 1995; Adams, 1996).

Given these strands of difference within and across families, it is perhaps inevitable that relatives' perceptions of problems following injury often differ significantly from professionals (e.g. Sunderland *et al.*, 1984; Sherer *et al.*, 1998). This particular dimension of difference is often characterized by frustration for all those involved, an undermining of collaborative opportunities, and the identification of family problems (or problem families) by clinicians. Indeed, it is often complexities within the family-service relationship that feature in team discussions. In our work at the OZC, the notion of discrepancy in both intra- and interpersonal contexts described in Chapter 4 can provide a useful orienting point as it fosters a sense of curiosity amongst the team about differences between the client and their family, between family members, between the family and the service perspectives etc. As described later in this chapter, acknowledgement of and engagement in reflection of such differences may lead a system to begin to make changes.

A systemic response to family complexity and diversity

The diversity and complexity of these family experiences are significant as noted in a recent review of the ABI family literature. Oddy and Herbert (2003) identified a notable lack of theoretically guided and evidence-based family interventions. In selecting an approach to direct family work in neuropsychological rehabilitation, certain criteria are therefore advocated as necessary parameters. The approach should be (1) based on theoretical foundations drawn from both ABI and wider family intervention literature; (2) also founded on a conceptual framework that satisfactorily engages with the aforementioned

issues of non-linear complexity and diversity within and across families (and their relationships to services); and (3) supported by an evidence base.

A general approach to family work that is advocated here as meeting these criteria is *contemporary systemic family therapy*. Comprehensive introductions to systemic family work are provided elsewhere (e.g. Boscolo *et al.*, 1987; Jones, 1993), and a brief systemic commentary on the ABI family literature is provided by Yeates (2007). Key features of the systemic approach will be summarized below in advocating the model's suitability for the aforementioned criteria. This approach to systemic work is predominantly associated with key publications from a Milan-based group of therapists (Selvini Palazzoli *et al.*, 1979, 1980; Boscolo *et al.*, 1987; Cecchin, 1987) and conceptually formative or successive approaches, such as cybernetics (Bateson, 1972), social constructionism (Gergen and Davies, 1985) and narrative therapy (White and Epston, 1990).

Using these ideas collectively, the problems and issues raised by families in conversation with services are conceptualized as only intelligible within the social contexts in which they occur, characterized as they are by dimensions of difference and interactional complexity. This complexity is understood in terms of feedback processes, positive and negative, that operate within systems to lead to the development or maintenance of the phenomena that those in the system are experiencing. These influences are considered to be socio-communicative (verbal and non-verbal), with language and communication conceptualized as constructing particular realities for system members. These social meanings are often characterized by diversity within and across families. Certain languages or conversations are understood to be inherently more powerful and influential than others, in both family and larger social contexts.

Finally, the concept of family system is no longer considered to represent a contained group that a professional service may assess and formulate with little influence on that system pre-intervention. Following the thinking of second-order cybernetics and all consecutive developments (e.g. Von Foerster, 1982; Boscolo *et al.*, 1987; Cecchin, 1987), 'observed systems' have been replaced with the idea of 'observing systems'. The latter refers to families in liaison with services. Family experience and the problems identified in conversation are inevitably shaped and influenced by the presence of professional involvement, privileging certain conversations and explanations above others.

How then can these ideas and epistemological positions be fruitfully applied within neuropsychological rehabilitation? An indication of the value of systemic thinking for this area of practice is provided through a growing collection of family systems, conceptual papers and single case study therapy analyses in the ABI literature (Williams & Kay, 1991; Gan *et al.*, 2006) Furthermore, certain authors have specifically highlighted the unique contribution of Milan and 'post-Milan' systemic ideas in ABI work (Gan and Schuller, 2002; Laroi, 2000, 2003; Yeates, 2007; see also Chapter 18), while others have used ideas central to this tradition in research analyses (Krefting, 1990; Yeates *et al.*, 2007). The evidence base for systemic family therapy with other clinical groups includes 'gold-standard' level I (American Psychiatric Association, 1996) studies (see Carr, 2000a, 2000b), but studies of this category are currently lacking within the ABI literature. Nevertheless, the broader evidence base for this approach warrants further efforts in applying these ideas within ABI work.

In so doing, services can begin to conceptualize the intricate web of contextual influences within families and between families and the services themselves in any form of liaison post-injury. Additionally, diversity in family contexts as a product of both inherent social differences and idiosyncratic complexity in familial relationships would be expected,

and prioritized as a source of reflection for services. Consistent with both the aforementioned positive outcomes for families and the post-modernist position of not prioritizing one particular reality or standard for all families, the unique strengths and resources inherent to a given family can be attended to in therapeutic conversation. This is in contrast to a deficit-focused position, assumptions of a 'dose–response' model, or other trappings of interactions based on a notion of 'expert intervention'.

Finally, a systemic approach offers a set of theoretical resources to formulate the experiences of the people with ABI themselves within a contextualized frame. In so doing, it is then possible to move away from the common 'partitioning' of the experiences and needs of relatives and people with ABI that often occurs in both the literature and the structures and practices of clinical services (Yeates, 2007).

Integrating neuropsychology into systemic family work

To achieve such aims for systemic family work in ABI services, neuropsychology must play a central role if the person with ABI is to be included (Johnson and McCown, 1997; Laroi, 2000, 2003). The language of neurological systems, the corresponding functional and psychological outcomes and the influences of neuropsychological impairments all need to be conceptually extended beyond the individual organism to the psychosocial realm. However to produce a biopsychosocial account consistent with a systemic position, the cumulative and constructive nature of psychosocial processes must be prioritized as a significant dimension in which material neurological damage becomes a subjective reality for the person with ABI, their family and those services involved.

Accordingly, initial questions for a systemic formulation of family experiences for ABI include: how do specific neuropsychological impairments undermine or influence key psychosocial processes and so maintain the experienced problems within a system? and how can these impairments be circumvented/compensated in order to enrich/strengthen a particular conversation/story or process of change (be this in a family session with services or within the home)?

Specific examples of such considerations include the role of expressive or receptive language difficulties or problems with encoding, storage or retrieval of memories. These can limit a person's access to and participation in the progression of certain conversations and the social maintenance of certain meanings and collective memories (Edwards and Middleton, 1986; Middleton and Edwards, 1990; Sabat and Harré, 1992; Harré, 2002). Thinking about the place of an impairment in a specific social context can lead one to considerations of empowerment for the family member with ABI, in terms of their ability to influence what is spoken about, jointly remembered, what meanings and explanations for things are offered and prioritized, and then in turn how this position may influence broader family responses.

Further examples include the conceptualized social mediation of executive functioning (Luria, 1961, 1968, 1976) within particular family contexts, and the interpersonal framing of social cognition deficits (Brothers, 1997). Visuo-spatial difficulties can be linked to shared or diverging realities within families and resultant relational positions (e.g. isolation, mistrust) for each member (a helpful theoretical resource can be found in Gibson, 1979).

Using these ideas to locate neuropsychological impairment within the active psychosocial processes in families, clinicians can then begin to strategically consider the role of specific cognitive rehabilitation strategies as a core component of family consultation. However, a systemic stance would caution against expecting a linear dose–response

relationship when considering both family diversity and the meanings to a given family of a particular rehabilitation intervention 'imparted' by brain injury professionals. Accordingly, a further dimension to the selection, use and framing of a rehabilitation intervention to a family, would be a consideration of how the socially constructed meaning of that intervention would be helpful or otherwise for each family member, regardless of the underlying neuropsychological rationale.

Working systemically within neuropsychological rehabilitation

In summary, key ideas from systemic family therapy and related traditions can be integrated with neuropsychological perspectives to formulate complexity, identify reciprocal circular influences, and maintain sensitivity to difference and diversity in families following ABI. Furthermore, this perspective is advocated as conducive to self-reflection regarding the inevitable influences of a neuropsychological service's involvement on family life, when responding to identified issues and problems.

Such foci can be used as foundations for emerging family-service conversations that will hopefully be useful in approaching the nature of family experiences after ABI. Points of meeting and conversation relevant to or between families and services in the post-acute period include initial contact, the feeding back of assessment data, initial, mid-, end- and post-programme reviews during rehabilitation, goal setting conversations, formal family educational or therapeutic sessions, conversations about relatives in individual client sessions, conversations about clients in relatives' groups, conversations about families during cross-service liaison, together with points of face or telephone contact during unexpected times of crisis.

At the OZC we have developed a comprehensive procedure for engaging and working with families and carers founded upon the literature and our clinical and research experience with families and carers. Extracts from this are included in Appendix 10.1 to illustrate our application of this literature in practice. Examples of different ways in which consideration of impairments in social contexts influenced rehabilitation and family consultation provided at the OZC are briefly described in Chapter 19, with further detail in the case of Simon (Chapter 18) and in our work with VO (Dewar and Gracey, 2007) who presented with significant retrograde amnesia, prosopagnosia and acquired deficits of social inference which carried varied meanings across the members of her family.

It is our experience that different families or family members have identified different points of contact as significant despite the initial intended aims of such meetings within broader service structures. As a service, making sure we offer a range of possible types and aims of contact thus becomes important. We have mapped the potential points of contact between families or carers and the Centre, presented in Tables 10.1 (contacts prior to the programme) and 10.2 (contacts during the programme and in the post-programme follow-up phase).

Several specific suggestions for practice can be made in relation to these differing points of family liaison during neuropsychological rehabilitation. Initial family meetings, regardless of purpose, can be significant for a family within a prior context of little service involvement and, for the service, can provide a great deal of information that will be key in guiding all future liaison. A systemic approach to these can be drawn from the suggestions of Anderson *et al.* (1986), who advocate the mapping of the dominant ideas and language present in family conversation as the problems are identified and described by different family members. Noting who has attended the sessions, who is absent, e.g. children are often excluded (Daisley and Webster, 2008), dominant definitions of the problem and

Table 10.1. Points of contact of OZC team with named carers and relatives prior to rehabilitation

Point of contact	Person responsible	Type of contact	Purpose of contact
Prior to PA	IPC	Letter and telephone	Clarify referral and attendance at PA
At PA	IPC	Face-to-face interview	Gather information about perception of client's difficulties, their goals, rehabilitation issues and previous services
		Outcome questionnaires	Gather outcome evaluation and relative assessment information
		Report	Inform re: results of assessment and recommendations
Prior to DA	IPC	Telephone or written	To confirm accommodation and support arrangements
During DA	IPC	Telephone or face to face	Gather information re: relative's goals for client, their needs, perception of strengths and weaknesses, current functional difficulties and involvement of local services
	IPC	Outcome questionnaires	Gather outcome data from relative
Towards the end of DA	Clinical psychologist	Face to face (with client as appropriate) or telephone contact	Gather information about pre-injury characteristics, cognitive abilities and coping style of client and developmental factors Share formulation and elaborate the formulation as a component of family context, including other people's responses and coping Discuss how the relative perceives rehabilitation, reflections on experiences with services to this point, and their expectations of this service

Table 10.1. (cont.)

Point of contact	Person responsible	Type of contact	Purpose of contact
At the end of DA	IPC	Summary of assessment feedback meeting	Present and discuss biopsychosocial formulation and recommendations Reflect with family members and client on emotional impact and meaning of the formulation Discuss goals for rehabilitation if returning for programme Clarify involvement of carer during programme (confidentiality issues), frequency of contact, their potential support needs; involvement in relatives group. Discuss nature and frequency of home visits
		DA report	Summarizes the formulation in written form, along with details of the assessment and a summary of the key points of the discussion and recommendations?
Prior to programme	IPC	Telephone & written	Clarify arrangements for starting the programme

PA=preliminary assessment, DA=detailed assessment, IPC=individual programme co-ordinator

associated explanations, together with subtle exceptions and variations from those dominant conversations, all serve as foundations for an emerging formulation of the family context. These questions help lead to a concurrent mapping of how family members are organized within these ideas, and the identification of power relations constituted through such constructions.

Cecchin (1987) and Hoffman (1990) prioritize clinicians' reflexivity of how they themselves are positioned and create influence within this process of enquiry. Reflecting upon powerful invitations by the family into certain accounts of family life and not others, the assumptions and premises underlying such invitations, the timing of requests for professional intervention and how the involvement of services reciprocally influence the maintenance of dominant explanations will be helpful in locating the

Table 10.2. Points of contact of OZC team with named carers and relatives during rehabilitation

Point of contact	Person responsible	Type of contact	Purpose of contact
During programme	IPC: initial telephone or face-to-face contact		To identify carer/relative's concerns and draw up a plan of contact (frequency, attendance at Relatives' Group, type & purpose of contact)
	Various members of clinical team: Home visit		A home visit is conducted (around week 6) during the intensive phase to identify and address any difficulties and reinforce strategy use in the home environment
	IPC	Mid-phase review (after 6 weeks)	Provide an opportunity for relatives, clients, case managers and team staff to review progress with goals, trouble shoot any early problems that emerge and review long-term care needs
		Progress meeting (after 12 weeks)	Provide information regarding client's progress towards achievement of goals, current issues and plans for integration phase, including contact with carers during integration phase and involvement in monitoring Identify potential involvement of carers and local services Information about progress of client and recommendations
		Outcome meeting (after 24 weeks)	Review progress and change. Review goal achievement Discussion of plans post-programme
		Report Outcome questionnaires	Gather standardized data re: relative's view of client's psychosocial functioning and carer stress (at weeks 1, 12 and 24)
	Clinical Psychology: Relatives Group		Invitation to Relatives' Group every 6 weeks (ideally weeks 1, 6, 12, 18 and 24 of programme) Peer support and general education about brain injury rehabilitation Support group for young people is also offered to young relatives
	Clinical team: Understanding Brain Injury Workshop		Invite relatives, carers and friends to attend 1-day Educational Workshop about mechanisms and consequences of brain injury. Educational Workshop is also offered for children

Table 10.2. (cont.)

Point of contact	Person responsible	Type of contact	Purpose of contact
	Relevant members of clinical team meet with family		As agreed in previous contact
Post-programme reviews	IPC: Face-to-face meeting		Clarify progress since discharge current issues and identify support needs, renegotiate goals if required
	Report		Summarize above and make recommendations
	Outcome questionnaires		Review progress and change

interrelationship of clinicians and family members, and the meaning to the family of particular interventions.

An integral dimension of this mapping is locating the language of brain injury, together with the consequences of using this language for each family member. This may involve asking questions such as 'Is this problem the result of the brain injury or some other reason? Is it because of the person they were before the injury? If this problem was due to x, y, or z, how would you respond in each case to him/her as a person, where does this leave each member of the family? Who agrees and who disagrees with these explanations, and how do these explanations make each of you feel? Is this a problem all of the time, or are there exceptions? On these occasions what is each person doing and what happens to the brain injury at these times? When is he/she most or least brain injured?'

The information gained from these questions can allow the clinician to map the continuity of pre-injury meanings in relation to the newer language of brain injury (central to variability in family experiences of 'personality change') (Oddy; 1995, Yeates *et al.*, 2007), and the interrelationships of different family members' subjectivities within these languages. This can be represented visually as a genogram, with competing languages located between different family members (an example is provided in Chapter 18). Furthermore, the differing relationships between the family and all services involved can also be represented in this way (Hartman, 1995). This is useful for both locating the neuropsychological rehabilitation service within a wider context of professional involvement, and also in identifying wider service provision gaps for individual family members (e.g. school support and child and family mental health services for children, advocacy and housing support for adults) or future sources of collaboration between brain injury and other services in jointly responding to family experiences.

These questions are sufficiently different in and of themselves to create change in families as new conversations are formed and family members are re-configured within these discussions, thereby dissolving the distinctions between assessment and intervention. These types of questions are examples of 'circular questioning', drawn from the work of the systemic authors (e.g. Cecchin, 1987; Tomm, 1987, 1988). Several types of circular questions are suggested, including the following (in the hypothetical case of 'Sam'): (1) mind-reading questions (e.g. 'what do you think she would say to the question I just asked you?

what would the old Sam have said to that? what would he think your answer to that question would be?'); (2) questions of degree and difference ('who notices first/is most sure that the brain injury is present in family life?'); (3) relational questions ('when Sam is most brain injured, how are his wife and child together?'); and (4) feed-forward questions ('how will you each know when there is an improvement? if the old Sam starts to return who would notice what?').

The aims of these questions are to gain relational information, emphasize the interconnectedness of family members, develop richness and diversity in family constructions and facilitate change. They may be effectively (but sensitively) used in any rehabilitation-related conversation (e.g. goal setting, review meeting, family supportive session), and can guide the decision of particular strategies to be used for certain purposes for optimal gain. However, these questions should always be informed by and consistent with a formulation of family interactions.

Further techniques for opening up diversity and richness in family constructions of problems and change can be achieved through the use of two or more clinicians. When it may be considered unhelpful to operate from a position of 'service as expert', for example when providing particular forms of advice, the usefulness of uncertainty and multiple perspectives can be powerfully communicated by clinicians. This may be through the use of 'reflecting conversations' (Andersen, 1987) between clinicians in the presence of the family, offering up all perspectives that have been previously discussed (including those that may have been lost under more dominant voices), holding these alongside one another while not validating one over another. Furthermore, reflections of disagreement and uncertainty between clinicians may be helpful for families who are stuck in thinking that there is one, elusive solution to their problems.

In the process of listening to the clinician's conversations, making choices from the possible constructions offered and in feeding back, the family becomes reorganized as a whole rather than fractionated through disagreements between members. The process of summarizing that is part of reflecting conversations has obvious additional neuropsychological benefits. During these conversations, the presence and energy of a large family can be quite overwhelming at times and often the clinician(s) involved can struggle to respond quickly while holding on to concurrent systemic hypotheses. It is worth noting that a traditional systemic session format (Selvini Palazzoli *et al.*, 1979) is constituted through five parts: (1) pre-session hypothesizing, (2) the first part with family, (3) a mid-session break where the clinician(s) leave the family and reflect on the content of the session so far, (4) a return to the family with any communications of the ideas reflected upon and (5) a post-session discussion. At the very least the use of a break in any family meeting is advocated as a helpful experience for both the family and clinicians.

The presence of multiple and differing perspectives can always be monopolized as a therapeutic resource. The use of meta-reflection, mind-reading questions, empty-chair techniques and prompts to consider perspectives held by those not present can be useful even if there is only one family member or one therapist (Boscolo and Bertrando, 1996). Similarly, different configurations of family members in sessions may be collaboratively agreed for different outcomes.

It is suggested that *this* is the rationale for deciding whether to arrange a family session with everyone present, with the person with ABI not present, with specific combinations of relatives or a group just for relatives across families. This collaborative decision-making involving all family members can be contrasted with the frequent decision by services to

arbitrarily define preset formats for family engagement. These different configurations may all lead to helpful yet different conversations at different points in time. It is suggested that where resources permit, all of these options are made available for families to choose to pursue during contact with ABI services.

A further recommendation that can be made in relation to systemic practice is in terms of how ABI educational interventions for families are framed and considered by clinicians. While the aforementioned professional positions of uncertainty have their value at certain times, at other times certain forms of information can be transformative in the context of a family's confusion and isolation from other forms of sense-making (Yeates *et al.*, 2007). However, a systemic position would caution against expectations of universal and linear dose–response outcomes for the provision of information, and would highlight the need to frame information to be optimally congruent with each family's own meanings. Such considerations are of relevance to the clinician (usually a clinical psychologist) providing one of the two types of relatives' groups run at the Centre (see Appendix 10.2). Different groups of relatives of clients from the programme are invited to get together once every six weeks or so. Sometimes the group is made up of relatives of current programme clients – there are some relatives who have attended regularly over longer periods of time, sometimes many years after their brain injured relative has completed the programme. Relatives' groups may involve, at the request of the relatives attending, 'expert' provision of information (although usually the relatives can obtain this through the Understanding Brain Injury day). Often though they are purely an opportunity for peer support and the sharing of stories and language for sense-making following brain injury.

As noted above, a final consideration in relation to all these practices is how neuropsychological understanding and cognitive rehabilitative practice is most usefully integrated to facilitate helpful conversations between all family members, including the person with ABI. Founded on a formulation of how specific neuropsychological difficulties are interrelated with surrounding interactional processes, specific systemic interventions can be advocated within both contextualized and neuropsychological rationales.

These include responding to memory or expressive language difficulties by attending and responding to familial processes of conversational repair, offering up other conversations or points of view reported by others in similar situations, framing things in a multiple-choice format, inviting questions that are not dependent on episodic recall (e.g. 'how would you feel typically in such situations? what would you advise to other people in similar situations?'). Furthermore, co-remembering can be facilitated through the identification and use of explicit cues at key points in an emerging family account (helpful for working memory difficulties specifically). It may be that communication and expression be less focused on the verbal medium, and instead 'visual' conversations are facilitated. The practice of 'spatial sculpting' from the structural family therapy school (Minuchin, 1974) may be of use in this case.

In the case of executive difficulties, the introduction of external problem-solving frameworks by clinicians, framed as 'for all family members', may be a helpful response to the well-intentioned efforts of relatives that may be experienced as patronizing or disempowering by the person with ABI. Similarly, if cueing or the provision of feedback by others is suggested, then the strategic identification of who in the family will most helpfully provide such feedback is a necessary prerequisite (Yeates *et al.*, 2007). It may be that the careful framing and use of pagers or alerts (e.g. Wilson *et al.*, 2001; Fish *et al.*, 2006) in both functional and psychotherapeutic work (Yeates *et al.*, 2008) may be the only form of cueing considered to be interpersonally viable (Yeates *et al.*, 2007).

A further technique may be of value to families where an awareness problem has been identified. Drawn from narrative family work, the use of 'externalizing' (White & Epston, 1990) involves the conversational repositioning of the problem outside of particular people, constructed as a source of difficulty affecting people collectively. The result of this reconstruction is that two or more people who were initially divided by the location of the problem in one person can then collaborate in unison against something external to themselves.

Externalizing conversations may be helpful for broader discussions about the effect of brain injury on all members of a family and how they might unite to reclaim aspects of family back from the injury. However, this technique may have specific value for awareness difficulties, where the family conversation can be framed as how family members can collaboratively respond to the externalized threat of 'disagreement' and its influence on family communication (Yeates *et al.*, 2007). In an interesting dove tail of family therapy and neuroscience, such a technique is also supported by experimental neuropsychological studies that show people with awareness difficulties to be more able to identify a problem if it is framed as external to themselves, such as in the third person, in a vignette or with reference to another person (Reisberg *et al.*, 1985; Marcel *et al.* 2004; McGlynn and Kasniak, 1991).

Summary

Distinctions in the ABI literature exist between different levels of family intervention such as the using of relatives as co-therapists, the provision of information, general support, family counselling and formal family therapy (e.g. Tyerman and Booth, 2001). It is advocated here that key ideas from the family therapy field can be applied to all forms of family liaison. In doing so, it is possible to work towards the post-modern aim of facilitating a helpful family conversation regardless of intervention, while avoiding the partitioning of relatives and people with ABI that is often visible in the literature and service structures. Systemic epistemology and practices are highlighted as appropriate in responding to both the complexity and diversity of family experiences following ABI, and specific applications have been suggested. This post-modern orientation by definition does not prioritize one perspective over another, and as such, although circular questioning and narrative techniques have been described here, a range of interventions may be appropriately used. Finally, the integration of systemic theory and neuropsychology is advocated as a necessary prerequisite to facilitate the emergence of helpful family conversations for all members, including the person with ABI.

Appendix 10.1: Extracts from the Oliver Zangwill Centre procedure for the involvement of family and carers in the rehabilitation process, and attendance at relatives' groups

1. **Background: Family needs after ABI**
   Family needs at the point of engaging with post-acute ABI services include:
   1.1. Confusion, uncertainty and a need for sense making
   1.2. Strain, burden, sub-clinical and clinical emotional difficulties
   1.3. Isolation from wider sources of support

1.4. Changes, tensions and breakdown within family interrelationships

Furthermore, these experiences are in reciprocal interaction with the referred problems and experiences presented by the family member with ABI themselves, and subject to neuropsychological rehabilitative intervention.

2. **Types of family or carer liaison**
Tyerman (1999) highlights the need for post-acute, community-based ABI services to engage in three forms of family liaison:

2.1. Collaborating with families in relation to client-centred neuropsychological rehabilitation (including the goal setting process)

2.2. Family information provision, ABI education and facilitating sense-making (to support development of a shared understanding)

2.3. Family support and if necessary formal family therapy

3. **Purposes of contact with family members and carers**
Involvement of family members may serve a range of purposes:

3.1 Maintaining a contextualized, psychosocial focus to goal setting and rehabilitation

3.2 Optimizing the social outcomes of clients and families

3.3 Supporting the emotional and practical needs of family members and carers – as identified at preliminary and detailed assessment, clarified at beginning of programme, and reviewed during the course of the programme and review period

3.4 Information gathering in relation to clients and relatives/carers specifically

3.5 Education about the programme and about brain injury

3.6 Providing specific information about a client's progress

3.7 Identifying contextual factors affecting the client's own emotional needs, adjustment and their application and maintaining use of strategies

3.8 Enabling them to support their brain injured relative as appropriate

3.9 Maintaining therapeutic relationships

3.10 Addressing any informal complaints or other feedback as part of complaints procedure

4. **Provision of family support within the programme (see Tables 10.1 and 10.2)**

4.1 The exact nature of family and carer support provision is based on a team systemic formulation of each family, including the client with ABI, and the relationship between the family and the service, although all forms of support are offered and negotiated with each family.

4.2 Family sense-making and support can be delivered through specific combinations of family liaison activity within the Centre:

- Contact during preliminary (PA) and detailed assessments (DA)
- Individual programme co-ordinator (IPC) weekly telephone contact
- Family contact during goal setting, progress, outcome and review meetings
- Understanding Brain Injury (UBI) education days
- Relatives' groups

- Family sessions arranged for specific rehabilitative aims
- Family therapy sessions

Appendix 10.2: Summary of relatives' groups membership and invitation (again from OZC procedure for the involvement of families and carers)

We offer two types of relatives' group:

1. For relatives, friends and carers of clients currently on the programme or who have completed the programme within the preceding six months. This group meets every six weeks.
2. For relatives, friends and carers of clients who completed the programme more than six months previously, or who have not attended the rehabilitation programme. This group meets every six months.

For group 1, invitation letters are sent to relatives of clients about to attend the programme. For group 2, letters are sent to those who have expressed an interest in attending for example following assessment of their brain injured relative at the Centre, but for whom an intensive programme is not being provided. The following is an extract of this letter:

What is the relative/carers group for? The sessions are shared with other relatives and have several purposes:

- One purpose is to give you the opportunity to ask questions about, or provide feedback on the rehabilitation programme that we run here.
- The second purpose is to provide an opportunity for you to ask questions about the nature and consequences of brain injury. As you know, we place strong emphasis in our programme on helping clients develop a good understanding of their brain injury. We also feel it is extremely helpful for you as relatives to have this information, therefore, you will have the opportunity to ask any questions you might have about brain injury.
- The third main purpose is also to provide the chance to talk to other relatives and share experiences with others who are in a similar position.

Attendance at these sessions is entirely optional, and coming to one session does not commit you to attending future sessions. We are aware that because of the distance involved and other commitments, it may not be possible for you to attend. In addition, some relatives and carers prefer to have such conversations within their own family rather than share experiences with others. We can arrange individual family sessions if this is preferred. Further forms of relative's support include educational days on brain injury, and details of these will be provided separately.

However, we feel that all forms of support have their own particular merits, and would encourage relatives to experience all of these at some point during the programme.

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Chapter 11

Communication Group

Clare Keohane

It is now widely acknowledged that the communication difficulties experienced following a traumatic brain injury (TBI) are fundamentally different to those associated with aphasic syndromes and consequently require different types of assessment and interventions (Holland, 1982). Milton and Wertz (1986) highlighted these differences suggesting that 'Individuals with Aphasia usually communicate better than they talk and TBI patients frequently talk better than they communicate' (p. 223). The most common injury aetiology of clients attending the Oliver Zangwill Centre for Neuropsychological Rehabilitation is TBI and therefore clients more commonly present with this latter type of cognitive communication impairment, rather than the more specific aphasic syndromes. Working with these clients requires awareness of the interplay between impairments in psycholinguistic processing and other cognitive domains in relation to communication.

The cognitive communication disorders observed in clients at the Oliver Zangwill Centre are typified by:

- Difficulties in language processing – in particular with inferential or metaphorical language.
- Difficulties with discourse – e.g. over inclusion of information, tangential output, irrelevant responses, inability to maintain a topic, difficulty turn taking, increased self-disclosure, reduced initiation.
- Pragmatic difficulties – i.e. adapting language to different environments, and different people, reduced flexibility in adapting language.
- Naming difficulties.

It is common for clients to present as socially isolated, with difficulties in relating to others and maintaining good work or social relationships. This is thought to significantly reduce life satisfaction (Dahlberg *et al.*, 2006).

Although the majority of communication problems of clients attending the Centre fall into the broad category of 'cognitive communication' difficulties, a proportion of clients present with dysarthric difficulties and, less frequently, problems of an aphasic nature.

A substantial number of clients present with dyslexic difficulties. These are usually addressed in individual sessions usually through identification of a functional goal relating for example to study, reading with children or dealing with correspondence.

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Recently, there has been significant development of knowledge in the area of socio-emotional processing, or social communication (e.g. MacDonald and Flanagan, 2004). This refers to an individual's ability not only to understand his/her own emotion and behaviour, but also to be able to regulate emotions and understand others' emotions and behaviours. Assessment of these skills and the impact of deficits on social interactions are explored jointly from both speech and language therapy and clinical psychology perspectives, reflecting the need to refer to a range of relevant social cognitive communication models and draw on the clinical skills of both professions.

Inclusion in the Communication Group

The process of addressing communication difficulties begins during the clients detailed assessment with exploration of the client's ability using standardized tests of cognitive communication skills. During this period, all clients are assessed using the Measure of Cognitive Linguistic Ability (MCLA; Ellmo *et al.*, 1995). If required, specific measures of object naming are also used (e.g. Boston Naming Test; Kaplan *et al.*, 1983; Graded Naming Test (first published in 1983); McKenna and Warrington, 2007). The introduction of The Awareness of Social Inference Test (TASIT: MacDonald *et al.*, 2002), which assesses facial emotion perception and the ability to make appropriate inferences from facial and voice communication in others has proved useful in determining areas of deficit in social communication. The results of this assessment are explored alongside other assessments relevant to social communication such as the Bangor Gambling Task (Bowman and Turnbull, 2004) and the Mind in the Eyes Test (Baron-Cohen *et al.*, 2001). The aim is to clarify whether functional communication and interaction difficulties are related to general cognitive impairments, e.g. with inhibition, speed of processing, or traceable to specific deficits in social processing, such as emotion identification, social inference, theory of mind, emotion-based decision-making, social knowledge, or emotional semantics.

As described elsewhere, due to the interactive nature of the clients' difficulties any information is shared with the team at the summary of assessment and links between other cognitive functions or mood issues and language discussed, e.g. attention difficulties impacting on language comprehension, anxiety affecting word naming skills.

Often, a formulation of clients' difficulties will include a description that the individual lacks 'communicative competence'. This is defined as 'a knowledge of how to converse with different partners and in different contexts and a knowledge of rights, obligations, and expectations underlying the maintenance of discourse' (Chapey, 1986). This communicative competence relies on a 'dynamic relationship between cognitive, linguistic, environmental and psychological processes' (Beukelman and Yorkston, 1991).

It is this area that is the focal point for the communication work in the rehabilitation programme and any deficits in this domain would lead to involvement in the Communication Group.

Communication Group

The Communication Group runs during the intensive phase of the programme and begins with an educational session pertaining to the clients' understanding of their brain injury. Specific links are made to the anatomy sections of the Understanding Brain Injury Group (Chapter 5) with particular discussions with regard to the areas involved with

language. An overview of the types of language difficulties clients might experience following any injury is given by staff, and clients are encouraged to discuss their own experiences and why they might have experienced certain difficulties. Clients are encouraged to explore through discussions and links to other groups how their communication problems may be linked to other cognitive difficulties.

In the initial Communication Group session the importance of gaining information from others' perspectives is discussed and agreement is sought to obtain information from relatives as to their perception of any changes or difficulties in the communications skills of the client. This is usually done through face-to-face or phone discussions with the relatives/carers. We devised a communication skills questionnaire related to the area of social communication. This is routinely given to relatives to enable us to explore premorbid communication styles more objectively (see Appendix 11.1).

In the second week clients are presented with a question 'What is communication?' and asked to brainstorm their thoughts. Following this a number of communication principles are listed to debate (McGann *et al.*, 1997; see Appendix 11.2). These principles are proposed to be 'constant and existing independently of personal skills and communication abilities' and 'serve as the universal precepts which underlie human communication'. It is recognized that clients will have developed, prior to their injury, a set of rules, beliefs and attitudes which defined how they interacted with those around them and that these will differ between clients. Over time, clients begin to recognize how communication can differ between people, but still be 'normal', and how it is affected by people's culture, environment and beliefs. Also discussed are how communication skills may be affected by brain injury and how communication behaviours may then not be consistent with communication principles. If for example a client presents with interrupting behaviours this might be explored in relation to the principle that 'communication is a shared experience', with a discussion of how interrupting might affect that principle. Discussion can then focus on why interrupting behaviours may be occurring and what cognitive difficulties might be contributing to this. At this point the term 'communicative flexibility' is introduced as an ideal skill to enable adjustments in communication to be made dependent upon either the situation we are in or the people with whom we are interacting. This usually leads onto a discussion about how the remaining group sessions will be used, and how the sessions will relate to work being undertaken in individual sessions (see below for details). Clients agree on the aims of the group and how feedback is used in the group context. Video feedback is felt to be the most useful tool in gaining awareness of difficulties and learning ways of managing them and clients are asked to sign a consent form for video to be used in their treatment.

Over the years the Communication Group has focused on differing aspects of communication depending on the needs of the clients. The most frequent themes covered have been work on assertiveness skills, conversational skills and social problem solving. Topic areas commonly worked on within the assertiveness skills module have been exploring the different behaviour types (passive, aggressive, indirectly aggressive, and assertive) and the underlying beliefs associated with assertive behaviours (Holland and Ward, 1990). Role-plays and discussion of real-life scenarios are fundamental to this work and both staff and clients engage in these activities together. This type of work often leads into the topics covered in the social problem-solving module where clients begin with bringing a real-life problem experienced in a social setting and explore alternative ways of dealing with a

problem incorporating communication, cognitive skills and discussion of the emotional impact certain situations can lead to.

The conversational skills module includes work on listening skills, initiating conversations, turntaking, maintaining and repairing conversations and the effects of interrupting, tangential speech and passivity on interactions. On occasions, debating sessions have been utilized to target specific communicative styles and difficulties in self-monitoring and organization of discourse. On other occasions the focus has been on communication in the workplace or at interviews – often incorporated into the Vocational Skills Group (See Chapter 12). Specific aims/objectives of the group are always highlighted with individuals' goals being linked to work being undertaken in individual therapy sessions. Evaluation of the group is through readministering rating scales and through goal achievement. Recently we have moved to using the La Trobe communication questionnaire (Douglas *et al.*, 2000) to aid us in evaluating progress.

Examples of the **general** aims of the groups have been:

- To identify our own communication behaviours and how they differ in the different roles we find ourselves in
- To identify and understand the principles of communication
- To improve communicative flexibility
- To apply our knowledge of communication to situations we find ourselves in
- Provide opportunities to practise and utilize effective communication skills.

Structure of sessions

The Communication Group is always an interactive group making use of role-plays and video or audio feedback to help clients evaluate their performance. All the sessions begin with a reflection on the topics covered the week previously and any homework set. Initially the focus is on clients' observation of others' communication – clients are asked to report back examples of where they have observed certain behaviours in others and the effect of these behaviours. As the group programme progresses the focus shifts to the clients' own communication skills and they are encouraged to seek feedback from each other before staff offer comments or feedback. In this way peers usually highlight any problem areas, which for many clients has more impact than if they are highlighted by staff.

Links to other sessions

Work carried out in the Communication Group needs to be linked into the individual therapy sessions that are carried out in the Centre. As noted previously the interplay between deficits in cognition and communication behaviours is an important area to highlight for the client.

As part of these sessions the communication questionnaires mentioned previously are discussed. This is particularly helpful with clients who lack awareness of their communication difficulties. Questionnaires are compared and priorities for therapy are identified. This process requires sensitivity on the part of the therapist and strengths as well as weaknesses are always highlighted with the client. Following the evaluation of these questionnaires, clients may decide to monitor one particular communicative behaviour for

a week or two and gain information about the situation in which the behaviour occurred and factors that might have impacted on it. Clients then move onto discussion about strategies that may help them improve communication skills and manage particular communication problems. Next, clients are encouraged to practise strategies within the Communication Group and other targeted sessions within the Centre before moving onto generalizing strategies to wider contexts.

Specific goals are agreed and set during these individual sessions and linked to the group work. Any sensitive issues that may have arisen can therefore be discussed outside of the group context.

Relative and other involvement

Clearly, any intervention in the area of communication after brain injury must take into account premorbid communicative performance. Often clients will present with a communication style that they report has always been 'part of them'. To this end it is vital that we draw on the observations of close relatives and friends in determining appropriate communication goals. Often when discussed with relatives a specific behaviour is noted to indeed have been part of previous personality, or communication style, but may have become exaggerated. Clients are encouraged to seek information from family and friends either through communication rating scales/questionnaires as noted previously or through joint sessions with the speech and language therapist. During the integration phase of the programme, where clients are beginning to utilize strategies, involvement of work colleagues, a college tutor or family/friends is helpful in providing feedback on performance.

If a client has returned to work or is involved in a work placement, communication skills are a focus for feedback as part of the work evaluation form. Similarly, clients may have partners who are involved in specific feedback sessions on a regular basis in order to ensure strategies are utilized effectively or adjusted accordingly.

Generalization

The Oliver Zangwill Centre programme is split into intensive and integration phases, which allows continued monitoring of how skills may generalize into other settings during the latter part of the programme and beyond. Clients can target specific situations during the integration phase where they wish to evaluate their use of strategies or skills developed and can continue to discuss any areas of difficulty with these during the days they still attend the Centre. Clients' predictions of communication behaviour and skills can be reflected upon in light of objectively gathered information about a situation. In this way, awareness and generalization can be developed through experiential learning cycles (see Chapter 4), and clients can be supported to develop more realistic, adaptive and confident perspectives on their communication. Usually clients are encouraged to continue to gain feedback from people in other settings following discharge from the programme and any issues discussed at the review appointments, 3, 6 and 12 months after completion of the programme.

Appendix 11.1: Communication rating scale

Please rate how you see … … … … … … …. performing in the areas below. Use the following rating scale and record your answers in each box provided.

1 = No difficulty. Never any problem.
2 = Minor Difficulties. Occasional Problem.
3 = Moderate Difficulties.
4 = Major Problem noted by others.
5 = Continual Difficulty. Occurs every day at least.

Circle the appropriate rating					
Think about whether or not what he/she says is understood by the listener. How often does he/she need to repeat what he/she has said?	1	2	3	4	5
Is the volume of speech ever too loud or too quiet?	1	2	3	4	5
How smooth is his/her speech and is it even?	1	2	3	4	5
Does he/she ever have difficulty in finding the correct word?	1	2	3	4	5
How easy is it for him/her to find appropriate topics of conversation?	1	2	3	4	5
How easy is it for him/her to introduce new topics into a conversation?	1	2	3	4	5
How easy is it for him/her to stick to one topic in a conversation? Do they wander off the point?	1	2	3	4	5
How equal or one-sided are conversations?	1	2	3	4	5
How easy is it for him/her to repair a conversation or misunderstanding?	1	2	3	4	5
Think about how often he/she interrupts another speaker.	1	2	3	4	5
Think about how easy it is for him/her to give both verbal and non-verbal feedback in a conversation.	1	2	3	4	5
Think about how well he/she listens to others.	1	2	3	4	5
Think about how easy he/she finds it to state how they feel.	1	2	3	4	5
Think about how easy he/she finds it to question things said or to ask questions spontaneously.	1	2	3	4	5
Think about how easy it is for him/her to use non-verbal skills e.g. eye contact, facial expression and how easy he/she finds it to converse.	1	2	3	4	5
THANK YOU FOR COMPLETING THIS QUESTIONNAIRE					

Appendix 11.2: Communication Group: communication principles

1. Communication is a shared experience
2. Communication is uniquely individualized
3. Communication reflects an accumulation of attitudes, values, beliefs and experiences
4. Communication can have as much impact on the environment as the environment has on communication
5. Communication is subject to interpretation.

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Chapter 12

Practically based project groups

Donna Malley, Andrew Bateman and Fergus Gracey

Introduction

Previous chapters have described the principles of neuro psychological rehabilitation and outlined the Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation programme providing descriptions of groups developed to address specific types of difficulties experienced by many individuals following acquired brain injury. In addition, within a holistic neuropsychological rehabilitation setting, other groups may be run according to shared needs of the individuals undertaking the programme at any one time. This chapter aims to identify some of the types of groups that have been utilized and discusses the format, content and ways in which such group work can be integrated within individual rehabilitation programmes. Group attendance is discussed and agreed as plans of action towards individualized client goals, which help to co-ordinate the activities of the clinical team.

Within society, people are members of one group or another, within the home, at work or in recreational and social interests. Groups provide us with a shared identity and roles, in addition to peer support, and we know that many people experience a loss of role and purpose and a sense of isolation after brain injury. Klinger (2005), summarizing the results of a qualitative study with traumatic brain injury participants, notes: 'participants had to learn a new way of "being" in order to move on to a new way of "doing"' (p. 14). A similar finding is reported by Gracey *et al.* (2008). Group activity is thus of central importance to the programme especially the 'therapeutic milieu' core component.

Groups can be classified in a number of ways, such as activity or supportive groups (Finlay, 1993) or formal versus informal (Rogers, 2002). Within the OZC milieu-based rehabilitation programme, there are groups that have an educational bias; they contain information of relevance to most participants, which will aid in their understanding of their injury and its consequences and introduce general strategies and methods that can be used to compensate for difficulties. Additionally there is a Psychological Support Group to provide participants with an opportunity to gain support through shared experiences (see Chapter 9). Other types of groups that run at the Centre include a daily community meeting, weekly review meeting, 'experimental' or project-based groups and functional skills-oriented groups. These latter groups involve participation in activity providing an

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opportunity to apply skills. As such they offer opportunities for experiential learning and change in accordance with the 'Y-shaped' model, as described in Chapter 4. Goal setting, planning, doing and reflecting provide concrete means of exploring perception of skills, awareness of strengths and weaknesses, a record of achievements, and feedback from others. Such experiential learning cycles occur within the group, and opportunities in groups may be used for behavioural experiments or projects set up in individual cognitive, communication or psychological therapy sessions. An example group summary sheet is provided in Appendix 12.1. This is used across all groups to help clients retain information learned and link this with other activities and goals. A brief description of these groups is now provided.

Community meeting and weekly review meetings

Community meeting

Rationale

The community meeting aims to demonstrate the principle of collaborative working between staff and clients, setting the tone for shared responsibility and problem solving within the Centre and thereby provides an important component of the therapeutic milieu. However, it does not discuss individual concerns, rather issues that may impact upon everyone within the Centre. In this respect it differs from the milieu opportunity described by Prigatano *et al.* (1986) and Prigatano (1999). One of the reasons for this may be considered cultural in that our service users tend to be more reserved and less willing to discuss issues in front of what may be a large group of people (including clients, staff and sometimes visitors). Opportunities to reflect on general Centre issues or items of interest provide an alternative 'safer' opportunity to facilitate interaction amongst members and build the trust and support considered prerequisites for sharing more personal and potentially emotionally challenging information in other sessions. Attendance at this meeting has also proven helpful to people considering referral to the Centre, to provide them with an opportunity to meet staff and current clients and see the collaborative ethos of the programme in action.

Aims of community meeting

- To provide an opportunity for participants and staff to exchange information which may affect the daily running of the Centre. For example, who is in the Centre that day, sharing of chores such as recycling of newspapers, and discussing any suggestions.
- To provide an opportunity to 'get to know' each other by talking briefly about a topic of interest or news item.
- To provide an opportunity to demonstrate the collaborative approach within the Centre.
- To provide a relatively safe and supportive opportunity for members to begin to practise skills and strategies they are learning prior to using them in settings outside the Centre.

Structure and content

The community meeting is held on a daily basis and involves staff, clients and any visitors to the Centre. The group can be chaired by staff and clients, with an agreed written agenda facilitating this process. Everyone is welcomed, new people introduced and absences

explained. Volunteers are requested for daily chores such as loading the dishwasher or collecting milk, and this is recorded using a visual aid (whiteboard) as a reminder. Items for discussion may be raised 'on the spot' or in advance via a 'suggestion box', and clients are supported to do this if necessary. An item of news or interest may be discussed or an update about the programme, such as aims for the week or group content. Typically, this meeting lasts for 15–20 minutes and is undertaken at the beginning of the day.

Weekly preview and review meetings

Rationale

During the intensive phase, a large amount of information is shared with clients and much discussion takes place. Clients fed back that this felt overwhelming at times and made it difficult to relate this work with their goals and ongoing journey through rehabilitation. For this reason, we added a preview of the coming week to the Monday community meeting, to help clients anticipate the areas that would be focused on in the coming week. We also added a specific weekly review session at the end of the rehabilitation week, on a Thursday afternoon, for clients to look back, discuss and reflect on their learning, goals and group interactions.

Aims of weekly preview and review

- To enhance encoding of key learning points from group sessions
- To support group members to take responsibility for note taking and feeding back to other clients
- For clients to make links between individual goal work and the content of groups
- For issues with the group learning process to be raised and addressed (e.g. how one client's impulsive interruptions may be impacting on group sessions, and how to work together to manage this).

Structure and Content

Agenda for weekly preview (as part of Monday community meeting)

1. Ask the leader of each of the groups: 'What is happening in the group this week?'
2. Strategy Application Group – Who is the secretary (and note-taker) for Strategy Application Group this week?
3. Of the remaining clients who would like to volunteer to be note-taker for:
   - Understanding Brain Injury (UBI) and Mood Groups
   - The two Cognitive Groups
   - Life Skills and Social Communication Groups.

Agenda for discussion of groups in Thursday's weekly review

1. Ask each allocated note-taker: 'Remind us what the key points were from (UBI, Mood, Cognitive, Life Skills, Communication) Group this week.'
2. Allocated note-taker to give brief summary to help group be reminded of what was covered.
3. Ask client group 'What are the main things that people have learnt this week from this group?'
4. Help the group discuss and reflect on what happened and what they learnt from this.

5. Watch the time!!! There are six groups and time is required for general discussion and reflection as well.
6. Prompt the group to help make sure each group member gets an opportunity to contribute to the discussion.
7. For the final 5 minutes or so, ask the group, clients and staff questions to facilitate general reflection and discussion of the programme, for example:
   - How are things going in general?
   - How are you working as a group?
   - How are you doing with your group goals?
   - Are there any concerns or questions?
   - Do you feel that the work you are doing fits with the goals you want to achieve?
   - Are there any other reflections or things that you want to take away with you or hold on to until next week?

'Experimental' or 'project-based' groups

Rationale

One important group opportunity involves use of a specific functional activity that acts as a naturalistic setting in which to conduct experiments to test out hypotheses about certain behaviours and their consequences. This behavioural experiment approach comes from an aspect of practice in cognitive behaviour therapy following brain injury (McGrath and King, 2004), and allows a safe and supportive environment to be created to enable individuals to try out strategies they are learning in individual sessions, applying them to other practical tasks, and linking this to salient meanings about abilities or identity. An example behavioural experiment sheet that we might use with a client across group and individual sessions is provided in Appendix 12.1. This draws on principles of discovery-based and experiential learning rather than a didactic style of information provision (Rogers, 2002). In this way it involves both generalization of skills to different settings and opportunities for repetition, which we also know to be sound learning principles. Groups that have been run utilizing this approach include Discovery Group, Newsletter Group, Strategy Application Group and Project Group, and there is some overlap in the aims, structure and content of these groups. A client-oriented goal planning process is necessary to ensure that individuals' goals are incorporated into the groups described, and that the learning from an 'experiment' or project is explicitly linked to the client's broader goals.

Discovery Group

Aims of Discovery Group

- The main task associated with this group is to complete an outing within agreed constraints and for participants to perform their identified roles successfully.
- Additionally, the aim of this group is to provide an opportunity for participants to gain feedback about their capabilities when working, as part of a team, towards a common goal, which is helpful when considering future vocational and recreational action plans.
- It also provides an opportunity to obtain feedback about their capabilities and to demonstrate application of strategies in a relatively 'safe' environment, before this feedback occurs in a more 'real-life' context outside the Centre.

Structure and content

This group has run on a weekly basis for an afternoon during the intensive phase of the programme. Participants are asked to plan an outing, which is completed the following week. The outing has to be completed within certain constraints, such as budget and time, encouraging a goal management approach to the task. Each member is allocated a specific role and tasks to perform as part of this role, for example managing finances or timekeeper. The outing is completed and then the following week evaluated against mutually agreed success criteria, including whether participants had performed their roles effectively (see Appendix 12.1). This provides participants with an opportunity to provide feedback on performance to each other and develop self-monitoring skills. In addition, it provides opportunities to develop skills in planning, teamworking, social communication, remembering and completing tasks, which are core skills for many independent living and vocational activities.

Newsletter Group

Aims of Newsletter Group

- The main task associated with this group is to produce a newsletter, meeting certain pre-agreed criteria within a given amount of time.
- The other aims of the group are the same as the second and third aims of the Discovery Group (see earlier).

Structure and content

This group has also run on a weekly basis during the intensive phase of the programme. As with the Discovery Group, participants share responsibilities for various tasks involved in collating a newsletter. Certain criteria are provided to give some structure to this project, such as contents suggestions and minimum length. Producing a newsletter is an ongoing project over several weeks and therefore incorporates planning, organization, prospective memory, time and goal management in addition to other cognitive, communication and psychological skills. Members are asked to reflect on their performance in allocated roles, such as chair of meeting or secretary, rotating roles amongst themselves, to provide different opportunities to self-monitor, practise skills and develop strategies. Staff members act as facilitators in this group, rather than taking a lead in the organization of work. Individual work with clinical team members will both reflect upon feedback gained during this project and discuss strategies to apply for tasks that need to be performed.

Project Group/Strategy Application Group

Sometimes Discovery and Newsletter Groups have been combined and called Project or Strategy Application Group. The aims are the same and the structure and content broadly similar, although a greater variety of project options has been introduced over time.

Structure and content

This group provides a variety of experiences for members and roles could potentially be geared towards individual capabilities and interests as necessary. It provides a direct vehicle for self-monitoring and application of strategies developed in other group and individual sessions, and opportunities for increasing awareness of strengths and areas of difficulty. As such, any

member of the clinical team could potentially facilitate such groups, and it has been useful to involve two disciplines, including occupational therapy, speech and language therapy and psychology. Typically, it runs for one hour on a weekly basis over a 12-week period. Additional individual time each week is encouraged to action tasks identified within the group.

Some discussion has occurred regarding how involved staff members should be in this group. Various options have been explored, from staff acting purely as observers or facilitators, taking on more directive roles or potentially being group members themselves. This last option enables modelling of desirable behaviours to occur. Therefore, the participants' needs are taken into account when considering staff involvement. Participants have evaluated their strengths and areas of relative weakness using self-evaluation forms to demonstrate progress over the course of the group. This written evaluation may be in response to open questions, such as 'What aspects went well/did not go well?', and 'How may I do things differently next time?', or using a work behaviours evaluation form (see Appendix 12.1) in order to make specific links to vocationally related skills. These evaluations are then discussed during individual sessions with team members.

Functional Skills Groups

Functional Skills Groups have been incorporated within the intensive rehabilitation programme alongside other group and individual therapy sessions. Whilst designed to increase individuals' awareness of strengths and needs and identify compensatory strategies, they tend to be skills-oriented, teaching participants some of the core skills required in order to cope with shared practical problems within the home, local community and at work. These groups offer a structured, supported and graded environment in which to learn or relearn skills required to complete everyday tasks. They also offer direct opportunities to try out strategies as applied to real-life problems and situations. Groups that have run using this approach include Leisure Group, Vocational Skills Group, Independent Living Skills and Study Skills Group. Skills and strategies introduced in these groups are then developed further during individual therapy sessions.

Within the Centre our role involves enabling people to undertake activities more competently, more confidently and more independently where possible. A key aspect is the ability to generalize skills and strategies to different situations to take account of changing roles and demands across a lifetime. In order to do this, clients need to be able to identify task demands, predict when problems may arise and put strategies into place prior to and during an activity (i.e. achieve anticipatory awareness; Crosson *et al.*, 1989). Our approach to all functional tasks is therefore to ask the following questions:

- What are the activities you wish to or need to undertake (considering independent living, recreational and vocational activity)?
- What are the steps involved in these activities?
- What skills do you need to undertake these activities (cognitive, communication, psychological, physical)?
- What factors affect these activities for you, bearing in mind your strengths and weaknesses (cognitive, communication, psychological, physical, environmental)?
- What strategies need to be developed for your chosen activities?
- Do these strategies work in context?
- What support do you need to maintain your ability to perform tasks after discharge?

Priorities for intervention are identified through clinical interview, structured using the Canadian Occupational Performance Measure or COPM (Law *et al*., 1998) alongside the client-centred goal planning process. This interview was selected because it is based upon a model, the Canadian Model of Occupational Performance (Canadian Association of Occupational Therapists, 1997), considered by the occupational therapists to be consistent with the holistic interdisciplinary approach of the Centre. It identifies functional tasks the client wishes to address, rated in terms of their relative importance to the client, and includes ratings of clients' perceptions of their performance and satisfaction with current performance. The COPM is used to quantify subtle changes in the client's self-perception of occupational performance (i.e. quality of performance as perceived by the client) that is otherwise difficult to capture, which makes it useful as an outcome measure. The COPM ratings are considered at the goal planning meetings and used alongside assessment information to identify realistic and measurable long-term goals for the programme. Typically these goals include development of skills and interests in independent living, recreational and vocational domains, and hence the development of group materials to address these shared concerns.

Independent Living Skills Group

Rationale

Following acquired brain injury clients frequently report problems in relation to managing daily living activities. These typically include planning and organization of daily tasks, dealing with correspondence, budgeting, shopping, meal preparation and management of household tasks. Some clients have developed the necessary practical knowledge, but the interactions between their cognitive and psychological (mood) changes make it difficult to complete tasks effectively, and so impact upon the quality with which tasks are completed and upon self-confidence. Use of formulation to develop a shared understanding of the factors influencing individuals provides a helpful context for both group and individual intervention. An additional consideration is that some people have had relatively little opportunity to develop or consolidate skills in these areas, primarily due to the age or life stage at which some of them sustained their injury. Opportunities to share experiences and knowledge and to develop strategies to increase independence, quality of performance and self-confidence are required and may be offered within a group context and/or via individual therapy sessions. This opportunity forms part of the therapeutic milieu approach, one of the core components of this holistic rehabilitation programme.

Aims of Independent Living Skills Group

- To enable participants to identify the demands associated with independent living skills.
- To enable participants to develop strategies to enable them to complete identified tasks with greater effectiveness, self-confidence and satisfaction.

Structure and content

This group runs for one morning per week and is run by an occupational therapist. Participants have an opportunity to identify which activities they have most difficulty performing from a list and so may decide in what order they wish to develop skills and strategies. First the participants review the previous week's session, then the therapist introduces the selected activity and ensures all members have an opportunity to

participate. At the end, there is a summary of the session, reflecting on key learning points for each individual. Each week an activity will be selected; the group will either engage in this locally or watch someone completing the activity, and then they will break down the task into its components and skills in writing. Opportunities to test out strategies relevant to that task are provided so participants can compare and contrast performance with strategy use to make informed choices, congruent with a collaborative approach rather than a 'prescriptive' approach. Homework is set to identify additional considerations specific to implementing this activity and strategies in their own community or home setting. This information is developed further in individual sessions so that the client develops a personal 'toolkit of strategies' they can use on discharge. The group provides functional activity opportunities where possible, so that the participants develop skills and strategies through engaging in the actual task. Generalization of skills and strategies is facilitated through clients being supported to apply their knowledge to specific tasks in their home community during the integration phase of the programme, which may include community-based intervention and liaison with local support services.

The list of functional skills typically included within this group are:

- shopping
- meal preparation
- weekly planning
- managing finances
- accessing community resources, including dealing with emergency situations
- route finding and use of public transport
- dealing with correspondence and form completion.

Leisure Group

Rationale

Many individuals report at assessment a reduction in their participation in desired recreational activities following acquired brain injury. Such activities may include physical recreation, such as attending the gym or playing sport, or social activities, such as going out to the cinema or meeting up with friends. Clearly there are a variety of interacting factors that may contribute to a reduction in participation in such activities. These include lack of money, access difficulties, loss of motivation, physical restrictions, in addition to the social, emotional and cognitive issues common to this particular client group. However, we know that engagement in pleasurable activity supports mood and self-esteem and is an important human occupation. Inclusion of a group focused on recreational activities is therefore often incorporated within the intensive phase of the rehabilitation programme.

Aims of the Leisure Group

- For participants to gain an understanding of what leisure is and why it is important to devote time to leisure in order to maintain wellbeing.
- For participants to gain knowledge of leisure activities and factors related to these including:
  - physical fitness

- healthy eating
- healthy living (including awareness of problems associated with alcohol and drugs)
- accessing leisure opportunities
- social skills

- For clients to have an opportunity to plan and carry out leisure activities individually and as a group.

Structure and content

Sessions normally run on a weekly basis for one hour per week, during the intensive phase of the programme. Participants are offered a range of topics for sessions under these broad aims, and invited to choose those they feel are most relevant to their interests and needs, or identify alternative topics of interest. Outside speakers may be arranged where they are considered to have a speciality in a chosen area, such as a dietician, drug and alcohol counsellor, or alternative therapist. Topics discussed have included healthy diet, promoting relaxation and sleep, smoking cessation, music, aromatherapy, art, tai chi and undertaking outings of interest in the immediate locality of the Centre. Independent work is encouraged to ensure relevant activities are followed up by participants in between sessions to enable them to practise new skills, consolidate new information and evaluate whether they wish to develop this area further during rehabilitation. Individual sessions further develop particular areas of interest and encourage access to local facilities and resources in the participant's home area, with a view to monitoring their participation during the integration phase of the programme.

Participants are encouraged to attend a gym induction session at the local community gymnasium following assessment by a physiotherapist. In the UK discounted access to exercise facilities is enabled through a referral scheme. The clients are especially encouraged to pursue an individualized physical fitness programme if this is one of their identified rehabilitation goals. Time is allocated within the group programme initially and support provided to participate in this programme as required. As many of us experience in New Year resolutions, motivation to continue to participate in an exercise regime is undoubtedly enhanced by peer pressure!

Vocational Skills Group

Rationale

The majority of people attending the OZC are keen to resume some kind of employment following their injury in order to provide them with a sense of purpose and role. Corr and Wilmer (2003) note the importance placed by adults of returning to work following stroke. O'Neill *et al.* (1998) explored the links between obtaining employment, and a person's perception of his/her quality of life and community integration. They concluded that there was a strong link between these variables and obtaining employment. However, one interesting finding was that those undertaking part-time work may have greater perceived quality of life and community integration than those who obtained full-time employment.

Aims of Vocational Skills Group

The aims of this group have varied according to when the group has run within the programme. Initially the group was run within the integration phase of the programme,

when participants were engaged in voluntary work experience or voluntary work trials and so one of the aims was a supportive opportunity to share experiences with other group members. Latterly the group has run during the intensive phase of the programme, and so the aims have been congruent with a long-term goal to enable participants to identify realistic vocational action plans by the end of the programme. Within this aim the objectives for the group included:

- Participants having a mechanism for appraising their current work skills
- Participants demonstrating knowledge of appropriate work behaviours
- Participants identifying strategies which can be applied in the work environment
- Participants receiving peer support towards their chosen vocational goals.

Structure and content

Participants in the Vocational Skills Group are those who have a long-term goal relating to employment. Whilst the group can be run by most qualified practitioners, the group tends to be run by an occupational therapist, with other team members leading specific topics of interest as required. The group normally runs for one hour per week during the intensive phase. It is structured such that it first reviews the previous week's session, then introduces new topics and ensures all members have an opportunity to participate. Towards the end there is a summary of the session, reflecting on key learning points for each individual. One participant is expected to summarize the session and feedback to other participants the following week, a role which is rotated amongst all group members. Participants are encouraged to use strategies to remember to complete individual feedback forms. Participants may also receive written handouts where appropriate to support their written notes. One of the strengths of this group is that it provides an opportunity to revisit information provided through other group sessions, thereby enhancing links and consolidation of new learning through repetition. The group is evaluated against its objectives at the end of the intensive phase and against the participants' achievement of their long-term goals.

Topics for group sessions have included:

- What is my vocational goal?
- What does work involve?
- What makes a good employee?
- How do other people perceive me?
- What can I do to help myself?
- Disability Employment Advisor – what happens after rehabilitation – who can provide support? Benefits and rights
- Applying for jobs, completing application forms and covering letters
- Interviews – preparing and role-playing the interview (what to say, what to wear, how to behave, how to prepare)
- What to say about my brain injury in the workplace – to employers and co-workers
- Work etiquette – what to wear, what to say, how to behave
- Job analysis and identifying strategies
- Implementing strategies in the work environment
- Resolving conflict in the work environment

- Work behaviours and problem solving in the work environment – including use of humour, asking for help, requesting time off, receiving constructive criticism, receiving positive feedback and being assertive in the work environment
- Anxiety management in the work environment
- Anger management in the work environment.

One of the methods to facilitate increasing awareness of participants' strengths and areas of difficulty is the work behaviours evaluation form (see Appendix 12.1). This form was designed to incorporate common work skills required within any work role, including work attitude, interpersonal skills and productivity. It can also be modified to include areas in more detail specific to individuals or their desired roles. It provides a five point Likert scale for participants and an independent rater to rate current skills based on observations within identified roles and responsibilities. Initially this may be introduced in the Vocational Skills Group or Strategy Application Group and used within Centre-related tasks, but can then be utilized within voluntary work environments. Voluntary work experience is undertaken in the second half of the programme, either in a local opportunity or the participants' previous work role if this is still available to them. The ratings and potential discrepancies between participant and independent-rater scores provide a useful basis upon which to target problem areas and evaluate strategy application. The information from these forms and voluntary work experience can then support production of a curriculum vitae and identification of a realistic vocational action plan, which are developed within individual therapy sessions. Much of this work could be considered 'pre-vocational' and so liaison with specialist employment services is undertaken prior to the end of the programme to ensure support is maintained for the client to pursue their vocational action plan following discharge.

Study Skills Group

Rationale

Some of the participants on the rehabilitation programme wish to explore educational opportunities either instead of or as part of a vocational action plan. They need to identify how the consequences of their injury are likely to impact upon their ability to engage in formal study, and therefore provide a rationale for learning compensatory strategies to cope with study-related demands. Formal study, as part of a vocational plan, usually comprises lectures, tutorials, independent reading, project work and some kind of examination process. These tasks are considered with reference to the typical difficulties experienced by individuals with acquired brain injury and suitable study skills can be introduced accordingly. Whilst participating in the intensive phase of the rehabilitation programme, incorporating group, individual and independent working, participants have an opportunity to reflect on their study skills during individual sessions, providing a rationale for further focused work on study skills strategies.

Aims of Study Skills Group

Study Skills Group provides an opportunity to:

- Experience study-related tasks, such as lectures, completing homework
- Reflect on how their strengths and weaknesses may influence such tasks
- Test out useful strategies
- Formulate an educational action plan.

Structure and content

The group runs during either the intensive or the integration phase of the programme, once a week for one hour per week. In the first few sessions, participants are introduced to a variety of different study skills and the situations in which these can be utilized. These include:

- What are study skills?
- Note taking – Why make notes?
- How to take notes – different techniques; abbreviations, listening skills
- Reading – how to read and take in information and write notes – different techniques
- PQRST (Preview, Question, Read, State, Test) for remembering written information
- Mindmapping and spider diagrams
- Writing and planning written assignments – how to start; brainstorming/mindmaps, identifying key words, defining topics
- Planning and organizing your study-time effectively
- Revising and making study notes and preparing for exams.

Exercises are provided to try out these skills, and homework set to provide further opportunities to 'test out' the strategies. A key reference for this group is *The Study Skills Handbook* (Cottrell, 2003). Later sessions provide an opportunity to test out strategies through engaging in a short course. This could be a course running in the local community, such as an adult education class running once a week for a couple of hours duration. Alternatively, an external tutor has run a short course for participants on the programme on a topic of potential interest, e.g. art history. The tutor conducts sessions using a 'lecture-style' or tutorial format and then sets homework each week. The tutor is also asked to set a piece of work for the duration of the short course, such as a short essay, and a 'test' at the end to see how much of the content is retained, from recall then with access to notes. These opportunities provide participants with concrete examples from which to reflect on their study skills in individual sessions. This then informs choice of future external courses and liaison with learning support departments is undertaken to ensure the client is supported following discharge from the programme.

Conclusion

The groups outlined here have all evolved from a need to provide concrete observable opportunities for both clients and staff to monitor skills and introduce compensatory strategies in a supportive environment. These groups provide the materials to observe and reflect upon in other sessions addressing awareness, adjustment and skills. Because they form part of an integrated holistic neuropsychological rehabilitation programme, such groups are difficult to evaluate in terms of their specific contribution to the achievement of individual client goals. Considering group aims and objectives and client feedback, they do appear to provide a useful and enjoyable opportunity to explore skills. Participants particularly report valuing group work that does not appear to have a primary focus on 'problems' and 'brain injury'. One of the benefits of introducing strategies within a group is to 'normalize' the process and utilize peers to share skills and knowledge. Additionally, the rationale for small group work and adult learning theory suggests such experiences do have a role within a client-oriented, collaborative rehabilitation process.

Appendix 12.1: Examples of handouts used for practically based project groups

Discovery Group responsibility checklist

Name:

Date	Responsibility	Independent	With cues	Assistance
	Money management: writes down assignment; estimates correct amount; asks administrator for money; asks for receipts; balances receipts and cash			
	Time management: writes down assignment; wears a watch; initiates plan with the group; ability to problem solve; flexibility			
	Directions: writes down assignment; knowledge of directions; can draw clear, concise map; can write or provide verbal instructions			
	Phone calls: writes down assignment; uses telephone book; asks appropriate questions; writes down information; feeds information back to group			
	Leadership skills: writes down assignment; initiates using the checklist; writes down information; allocates responsibilities to group members; feedback to Centre at community meeting; allocate writing article for newsletter			

Group/session summary sheet

Date———————————————————————————————————

This session/group is about

———————————————————————————————————

———————————————————————————————————

Summarize key points:

1.———————————————————————————————————

2.———————————————————————————————————

3.———————————————————————————————————

Homework tasks?

———————————————————————————————————

My personal 'take home message' for the session:

———————————————————————————————————

The next step in developing this:

———————————————————————————————————

(Prompt: Who? What? Why? When? Where? How? Questions may help you fill in this form)

Bring this form to 'weekly review' meeting to help us all remember what we did.

Work behaviours evaluation form

Name of client:.....

Date:.....

Name of person completing form:

.....

Please circle the performance rating according to the key below:

1. unacceptable
2. poor
3. fair
4. good
5. excellent

n/a not applicable

Please base your ratings on **the past 2–3 weeks** and give examples where possible.

Attendance

Ability to arrive and leave on time 1 2 3 4 5

e.g.———————————————————————————————————

Judgment in when to take breaks 1 2 3 4 5

e.g.———————————————————————————————————

Ability to tell supervisor of absence in advance 1 2 3 4 5

e.g.———————————————————————————————————

Overall attendance 1 2 3 4 5

e.g.———————————————————————————————————

Productivity

Ability to sustain concentration on tasks 1 2 3 4 5
e.g.———————————————————————————————

Organized approach to tasks,
including prioritizing effectively 1 2 3 4 5
e.g.———————————————————————————————

Ability to finish tasks 1 2 3 4 5
e.g.———————————————————————————————

Ability to initiate starting a new task when
the present task has been completed 1 2 3 4 5
e.g.———————————————————————————————

Ability to physically perform the task 1 2 3 4 5
e.g.———————————————————————————————

Ability to learn a new task 1 2 3 4 5
e.g.———————————————————————————————

Ability to remember what they are told 1 2 3 4 5
e.g.———————————————————————————————

Ability to follow instructions accurately 1 2 3 4 5
e.g.———————————————————————————————

Overall speed of performance 1 2 3 4 5
e.g.———————————————————————————————

Overall quality and accuracy of work 1 2 3 4 5
e.g.———————————————————————————————

Overall stamina 1 2 3 4 5
e.g.———————————————————————————————

Overall productivity 1 2 3 4 5
e.g.———————————————————————————————

Work attitude

Willingness to take on increased responsibility 1 2 3 4 5
e.g.———————————————————————————————

Ability to handle changes in the routine 1 2 3 4 5
e.g.———————————————————————————————

Ability to be self-motivated 1 2 3 4 5
e.g.———————————————————————————————

Use of initiative 1 2 3 4 5
e.g.———————————————————————————————

Interpersonal work behaviours (colleagues)

Getting along with others 1 2 3 4 5
e.g.———————————————————————————————

Ability to avoid distracting others 1 2 3 4 5
e.g.———————————————————————————————

Ability to avoid distraction from others 1 2 3 4 5
e.g.———————————————————————————————

Ability to control behaviour around others 1 2 3 4 5
e.g.———————————————————————————————

Ability to handle conflicts or disagreements with others 1 2 3 4 5
e.g.———————————————————————————————

Appropriateness of person's social behaviour and communication 1 2 3 4 5
e.g.———————————————————————————————

Interpersonal work behaviours (supervisor)

Ability to accept supervision from others 1 2 3 4 5
e.g.———————————————————————————————

Response to feedback about performance 1 2 3 4 5
e.g.———————————————————————————————

Ability to change behaviour when given suggestions 1 2 3 4 5
e.g.———————————————————————————————

Initiates asking for assistance when required 1 2 3 4 5
e.g.———————————————————————————————

Plan for the forthcoming weeks

Main issues raised from feedback :

Activities to be targeted over forthcoming weeks and agreed actions:

Signed: ..... (Supervisor)
..... (Client)

Behavioural experiment sheet

session date:

DATE Time	Situation/Task	Predictions or ideas about the situation or task	WHAT ACTUALLY HAPPENED	WHAT I LEARNT ABOUT:	
				myself	skills or strategies

PLAN – what am I going to do next?

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Section 3
Chapter
13

Case illustrations

Peter: successful rehabilitation following a severe head injury with cerebrovascular complications

Barbara A. Wilson and Jonathan J. Evans

Peter was one of the early clients at the Oliver Zangwill Centre for Neuropsychological Rehabilitation and this chapter gives a typical picture of the process of assessment and rehabilitation for our clients. We begin with a summary of the report from his preliminary (one-day) assessment as this details his major problems, his own and his wife's perceptions of his difficulties together with the staff's assessment of these.

Preliminary assessment report

History of injury

Peter was involved in a road traffic accident in July 1997 in which he sustained a severe traumatic head injury. At the time he was 33 years old. He was taken to the nearest hospital and then transferred to the Regional Neurointensive Critical Care Unit where he remained for one week, before being referred back to his local hospital. He stayed there for seven weeks. It is not clear how long he remained unconscious, but the notes from the Critical Care Unit say he had a head-on collision in a built-up area. His Glasgow Coma Score at the scene was 15 but by the following day had deteriorated to 11 and then to 7. It would appear that he had a post-traumatic amnesia of around 5–6 weeks. His retrograde amnesia, however, lasted only a few seconds. A CT scan of Peter's brain showed bilateral areas of attenuation in the temporo-parietal regions consistent with a cerebrovascular accident. This was subsequently found to be due to bilateral carotid artery dissection. In other words, Peter had sustained both a traumatic brain injury and a stroke.

Once back at the local hospital, it became clear that Peter was unable to communicate through speech or gesture. He also had a right hemiparesis, though his left side was moving freely. At this hospital he was seen by a neuropsychologist, an occupational therapist, a speech and language therapist and a physiotherapist. After Peter was discharged from hospital he received out-patient rehabilitation until December 1997. The

Neuropsychological Rehabilitation: Theory, Models, Therapy and Outcome, Barbara A. Wilson, Fergus Gracey, Jonathan J. Evans and Andrew Bateman. Published by Cambridge University Press. © B. A. Wilson, F. Gracey, J. J. Evans and A. Bateman 2009.

neuropsychologist at this hospital was responsible for Peter's referral to the Oliver Zangwill Centre.

Social history

Peter lived with his wife Linda. They had no children. Peter was a partner in a small engineering business. Although he was an engineer by training, his duties in his business were mainly managerial. He did most of the liaison with customers as well as a considerable amount of computer work. The company had taken on someone else, temporarily, to cover Peter's duties.

Presenting complaint of client

Peter identified the following areas of difficulty:

1. Speech. He tended to slur his speech when tired.
2. Telling the time. He found it difficult to tell the time from a clock face.
3. Memory. Not quite as good as it used to be.
4. Right hand. This felt numb and heavy and he had difficulty detecting temperature changes.
5. Reading and writing. He was much slower now.
6. Spatial awareness. He did not always see things on the right.
7. Processing information. He was slower at thinking and dealing with information.

Linda identified the following difficulties. To some extent these were the same as the ones Peter had identified.

1. Reading. This was slow and Peter forgot some of the information he had read. He did not always read to the end of a line; he tended to miss words and he sometimes missed a line so would drop down a line and read a sentence incorrectly.
2. Writing. This, too, was slow. He needed to learn to write again. He printed rather than used cursive writing. Some letters were formed in an unusual way.
3. Keyboard skills. Before his accident Peter used the computer a great deal at work and at home. Now he remembered the basic principles, but had lost his keyboard skills. He was gradually regaining these skills, but his use of the keyboard was slow.
4. Telling the time. Peter had difficulty telling the time particularly with an analogue clock/watch. He tended to get minutes to the hour and minutes past the hour confused.
5. Spatial orientation. Peter had a problem with directions. He confused left and right, up and down, and above and below.
6. Mathematics. Although able to use a calculator, Peter found basic maths difficult, particularly subtraction.
7. Alphabet. When writing the alphabet Peter tended to transpose some letters towards the end of the alphabet and often missed out a letter, usually 'w'.
8. Understanding. Sometimes Peter needed things to be explained several times in order to understand what was required of him.
9. Auditory retention. Peter did not remember much of a passage of text if it was read to him. His general memory, however, had improved and Linda considered this to be reasonable.
10. Manipulation. Peter had difficulty tying his shoelaces and combing his hair.

11. Spatial awareness. At first, Peter had severe right-sided spatial neglect but this had improved considerably.
12. Spelling. Sometimes Peter omitted or transposed letters.
13. Behaviour. Peter sometimes laughed at inappropriate times and had great difficulty stopping. Linda believed this was improving.

Client's goals

Peter said that his greatest concerns were reading and writing and keyboard skills. He believed that these areas of functioning were critically important if he were able to return to work. His goal was to return to work for his company, though he acknowledged that this may not be in the same capacity as before.

Linda felt that the following areas were the most important if Peter were to take greater control of his life.

1. To manage his appointments.
2. To speak for himself.
3. To improve his reading and writing skills.

Neuropsychological assessment

Although Peter had a brief neuropsychological assessment during the one-day assessment, we will leave these results for now and incorporate them in the neuropsychological assessment carried out during the two-week detailed assessment below.

Speech and language assessment

Peter's speech was fluent although slightly slurred at times. He gave a clear account of his perception of his communication difficulties.

Receptive language

Peter had no difficulty following conversations and understanding questions. He said that memory difficulties affected his ability to follow verbal instructions. He could follow films and television programmes but had poor recall of detailed information afterwards. He also said it was harder to follow conversations in group situations as he became more distracted.

Peter believed that his biggest area of difficulty was with reading; he found this extremely effortful and slow. He had to focus on each individual word and was unable to link two or more words together. As a result, he found it difficult to interpret what he read. Minor mispronunciations also occurred, most of which he rectified with effort.

Expressive language

Although Peter reported occasional difficulty with word finding, he believed he was aware when this occurred and he could access the word if he gave himself time. He felt that if he used the wrong word it was often associated in some way with the target word.

He thought his speech was worse when he was tired or in a noisy environment. The same was true of his word-finding problem. Peter believed that his biggest problem, however, was with written expression and this was due largely to the reduced physical functioning in his hand. He also seemed to have some difficulty in sentence formulation. When asked to provide a sample of written language, Peter found this difficult and although able to produce a sentence when prompted, his writing was extremely effortful and very slow.

Peter felt he had no particular social communication difficulties, but would now avoid situations in which he was unsure of himself. This did not happen before the accident.

Assessment of physical function

Peter said his main physical difficulties were numbness and reduced sensation in his left hand, slight weakness and pain in his left wrist and general reduction in physical fitness and stamina. When prompted to come up with examples of how these impairments affected his everyday life, Peter said that he had difficulty tying his shoelaces. He went on to say that this was more to do with his sequencing and visuo-spatial difficulties than to restricted physical function. He reported that he had no problems with other fine dextrous activities, such as buttons and fastenings. His handwriting, however, was less tidy and slower than it used to be and became worse if he wrote for any length of time.

Peter's main physical goal was to get back to full strength and improve his stamina. He said he was attending a fitness gym on a regular basis, in an attempt to achieve this goal.

On observation, Peter was physically independent around the Centre. On shaking hands with him, there appeared to be some mild increased tone in the right hand. On questioning, he reported that he was unaware of this and did not have any sensation of tightness, stiffness or restricted movement in his arm.

It was thought that Peter would benefit from a more detailed assessment of his physical functioning; in addition, he might benefit from advice regarding his physical fitness training.

Activities of daily living

Employment

Prior to his injury Peter was a partner in a small engineering company. His partner had taken on someone to help cover Peter's duties. As Peter was self-employed there were no deadlines for return to work. He realized that he was not fit enough to return at present and actually stated that when he was ready he would contemplate doing other aspects of the job if this should prove necessary.

Perception

Peter recognized that he had spatial awareness problems, and gave the example of bumping into things on his right-hand side. He said this had improved, but was unable to say whether it was still a problem. Peter wears glasses for distances. When asked about other senses he reported no difficulties, although he was aware that his taste was different in that he used to enjoy drinking tea but this was no longer the case.

Transfers

Peter was independent in all functional transfers, i.e. chair, bed, toilet, bath and car. He had grab rails and an extra banister rail fitted at home. Initially he needed to use a bath seat when bathing but was now independent. He was careful not to hit his head when getting in and out of the car.

Self-care skills

Although independent in washing and dressing, Peter needed assistance from his wife until 5–6 weeks prior to his assessment. He found tying shoelaces and manipulating buttons

difficult. He cleaned his teeth independently. For the previous three weeks he had been independent in shaving. He was able to wash and comb his hair, but found the latter difficult particularly when combing the back of his head; this may have been due to reduced sensation in his right hand.

Following the accident Peter needed to use adapted cutlery to feed himself but could now use normal cutlery independently.

Domestic activities of daily living

Prior to the accident Peter and his wife shared household duties. He was more involved with the garden, the car and doing DIY (do-it-yourself, i.e. home improvements) as well as some cooking and ironing.

Since his accident he had avoided tasks at home. He sometimes made a hot drink and very occasionally a sandwich. As he thought his physical problems might cause him to cut himself, he rarely did this. He had tried potting some plants in a tub, but found he was very slow. This made him feel frustrated.

Community activities

Transport

Prior to the accident Peter's main form of transport was his car. Since then his wife drove him. He had never used public transport.

Shopping

Peter and Linda shopped together for groceries, although Peter found it difficult to pack the bags apparently because of planning problems.

Financial management

Peter was still receiving pay from his company. He was also in receipt of Disability Living Allowance. Linda was currently dealing with their financial affairs although Peter said he would like to start taking on this role again if he could get over his problem with numbers.

Use of community resources

Peter went to a local gym with his wife 2–3 times a week. He could not think of any other facilities he used.

Hobbies and interests

Before the accident Peter had enjoyed doing DIY and flying a radio-controlled helicopter, both of which he was keen to start up again.

Summary of assessment and recommendations

In summary, it appeared that Peter had a wide range of cognitive and physical difficulties following his brain injury the previous year; in particular these problems were in the following areas:

- Abstract reasoning, particularly with visuo-spatial material
- Memory for verbal and visual material
- Speed of processing
- Initiating responses

- Attention, including spatial attention/perception and spatial awareness
- Calculation
- Reading
- Writing
- Left/right discrimination
- Upper limb sensory and co-ordination problems.

Despite the considerable progress made since the injury, these problems continued to have a major impact on Peter's life both in terms of activities of daily living and work. Consequently, it was recommended that he return to the Oliver Zangwill Centre for a two-week detailed assessment to identify his rehabilitation needs and his goals in more detail. Included in this two-week period would be specific assessment of the following areas:

- Memory functioning
- Attentional functioning
- Perception (including space perception, visual imagery, mental rotation and telling of time)
- Problem solving, planning and organizational skills
- Language functioning (further assessment of reading and writing to establish the degree of language impairment that exists, alongside other cognitive deficits)
- Mathematical ability
- Social communication
- Further investigation of impact of cognitive and physical problems on functional activities, including work-related activities.
- Establish in more detail Peter's long-term rehabilitation goals
- Establish opportunities for staged return to work environment if appropriate
- Establish Peter's ability to participate in the Oliver Zangwill Centre rehabilitation programme.

Peter and Linda were enthusiastic about the recommendations. We were able to obtain funding for the next stage of the programme, namely the detailed two-week assessment. Peter came to the Centre at the beginning of February 1998. Table 13.1 shows the plan of assessment to be carried out during this period.

Detailed assessment

The assessment was carried out during group and individual therapy sessions with all members of the multidisciplinary team. A summary of the assessment can be seen in Table 13.2.

In addition we present the neuropsychological assessment report undertaken during this two-week period.

Neuropsychological report

Peter was assessed over a two-week period between 9 and 23 February. Below are the results of his neuropsychological tests.

Table 13.1. Plan of detailed assessment

Date: 5.2.98 – Plan of assessment	
1.	Assessment of client's ability to formulate long-term goals (individual programme co-ordinator (IPC))
2.	Assessment of availability of appropriate local services in client's own community (IPC)
3.	Assessment of client's home and work setting, as appropriate (IPC and occupational therapist (OT))
4.	Assessment of relative/carer's perception of rehabilitation issues and likely involvement in rehabilitation process (IPC)
5.	Assessment of client's ability to engage in intensive rehabilitation programme (All)
6.	Completion of Outcome Scales (IPC)
7.	Neuropsychological assessment of: memory, attention, perception (including mental rotation and telling the time), executive functioning, mathematical ability (clinical psychologists and psychology assistants)
8.	Assessment of higher-order language ability (speech and language therapist (SALT))
9.	Assessment of social communication (SALT/All)
10.	Assessment of ability to manage financial matters (link with mathematical problems) (OT)
11.	Assessment of mood (neuropsychiatrist and clinical psychologist)
12.	Assessment of upper limb functioning (physiotherapist (PT))
13.	Assessment of need for further advice re physical fitness training (PT)
14.	Assessment of ability on specific functional task (task to be agreed with Peter) (OT)
15.	Assessment of community mobility (OT/PT)

General cognitive

Peter was assessed on the remaining eight subtests of the Wechsler Adult Intelligence Scale-Revised (WAIS-R) having undertaken three of the tests on his one-day preliminary assessment.

The scores reflect a verbal IQ of 79, a performance IQ of 80 and a full scale IQ of 77 putting him in the 'borderline' range. Given Peter's occupational achievements to date, such scores clearly represent a significant decline from his pre-injury level of functioning. In addition, given the nature of his occupation and education (Peter left school at 16), one might expect that premorbidly his performance IQ would have been superior to his verbal IQ.

Analysis of Peter's verbal subtest scores shows that his score on information was significantly lower than his other scores. This suggests difficulty with the recall of information although it could also reflect his level of education.

On the performance scale, Peter scored in the impaired range and did particularly badly on the Digit Symbol subtest. Low performance scores may reflect a slowed speed of problem solving which is clearly evident in informal observation. The Digit Symbol subtest taps visual

Table 13.2. Summary of the two-week assessment

Assessment number	Summary of assessment
1. Assessment of client's ability to formulate long-term goals	Peter has been able to identify a number of long-term goals which include the following: 1. To get back to work (though he acknowledges this may be in a different role than before, at least initially) 2. To relearn to drive 3. To be able to solve work-related problems 4. To relearn to fly his model helicopter 5. To do DIY projects 6. To improve his speed on the computer 7. To improve his writing and spelling, particularly the speed 8. To speak more clearly and confidently.
2. Assessment of availability of appropriate local services in client's own community	Peter lives about ten minutes walk from the local shops and the same distance from his workplace.
3. Assessment of client's home and work setting, as appropriate	Peter was seen at home and asked to plan and prepare a simple meal. He chose to cook an omelette. He was also assessed shopping. He was able to walk to the shops independently and was considered safe when crossing the roads. He only had two items that he needed to buy and, therefore, did not need to use a shopping list; he was successful in remembering the items. He was able to locate the items. When paying for the goods he said he found it difficult to get the money from his pocket because of the decreased sensation in his right hand. When actually preparing the omelette he organized himself. He was able to break the eggs. He cooked the omelette on a reasonably low heat which meant he had time to think through what he was doing. He found difficulty manipulating the spatula (? due to sensory problems in his right hand or dyspraxia). He seemed to forget that he needed to add the cheese but reminded himself when he saw it on the side. Peter was independent in making a snack, however, it would be useful to assess a task that requires more steps providing Peter feels this is an appropriate activity. By doing this we could look at his planning and organizational skills.
4. Assessment of relative/carer's perception of rehabilitation issues and likely involvement in rehabilitation process	List originally provided by Peter's wife, Linda.
5. Assessment of client's ability to engage in intensive rehabilitation programme	Very good engagement in all aspects of the programme.
6. Completion of Outcome Scales	Completed

Table 13.2. (cont.)

Assessment number	Summary of assessment
7. Neuropsychological assessment of: memory, attention, perception (including mental rotation and telling the time), executive functioning, mathematical ability	Assessment revealed deficits in abstract reasoning, particularly with visuo-spatial material; memory for verbal and visual material; speed of processing; initiating responses; attention, including spatial attention/perception and spatial awareness; calculation
8. Assessment of higher-order language ability	Peter was assessed on The Measure of Cognitive-Linguistic Abilities (MCLA) which aims to assess linguistic abilities and the effect of other cognitive deficits on language functioning, with the following results:
	Receptive Language: Peter displayed mild difficulties with auditory paragraph comprehension tasks and severe difficulties in story recall tasks. It was felt that his performance on the paragraph recall tasks was affected by his poor memory. This led to minor errors. His drop in performance on tasks requiring him to recall details of stories heard reflect this difficulty in memory. Peter also displayed mild problems on verbal abstract reasoning tasks.
	Expressive language: (c.f. Dysarthria assessment)
	Peter scored well on measures of discourse and on pragmatic rating scales. Samples of expressive language showed appropriate use of vocabulary, syntax and amount of information given. He was able to organize his language well and produced well-referenced cohesive sentences on both narrative and procedural discourse. In conversation no difficulties in these areas were seen. On visual confrontation naming tasks mild errors were seen with Peter requiring extra time to access some words. He was aware when he had made a mistake e.g. 'cufflinks' for 'handcuffs' and could correct his errors in time.
	Reading/writing: Peter described these areas as the greatest area of difficulty for him. Writing was very slow and effortful and in addition he reported having difficulty in 'thinking how to write letters and words'. On reading tasks on the MCLA Peter was able to provide correct answers from straightforward functional reading tasks but was very slow. With inferential passages some minor errors were made. It is uncertain whether this is due to difficulties in comprehension or because of his poor memory together with the laborious and effortful process of reading complex material.
	Peter was also assessed with subtests of the PALPA (Psycholinguistic Assessments of Language Processing in Aphasia) to determine his specific difficulties with reading and writing. He appeared to have a combination of dyslexic and dyspraxic problems that interfered with his ability to read and write fluently. On reading tasks there was no apparent word length effect. Peter was able to

Table 13.2. (cont.)

Assessment number	Summary of assessment
	read correctly some six letter words but was incorrect on some four letter words. The effects of imageability and frequency of words were, therefore, investigated. Peter's performance noticeably dropped with low imageability and low frequency words (e.g. miracle, wrath) as opposed to high imageability and high frequency words, (e.g. coffee, hotel). In addition, he had difficulty in making judgments between a lexical decision task (i.e. discriminating between real and nonsense words). He was also poor at reading irregularly spelt words compared to regularly spelt words. Spelling tasks reflected the same difficulty with low imageability and low frequency words. There was no word length effect on spelling. Irregularly spelt words were more difficult for Peter although his performance on regular words was not perfect. While engaged in written tasks, it appeared that Peter had some difficulty in deciding how to hold the pencil when writing, suggesting dyspraxia as he could obviously picture the target sound but was unable to produce it on paper. Peter showed evidence of letter reversal problems; he was usually able to inhibit or correct this, but was consequently slow.
9. Assessment of social communication	Peter showed little evidence of difficulty in this area. He reported that he finds himself yawning more than he used to which he was concerned could be interpreted as him being rude or bored. He did not believe this was due to tiredness levels as he observed it happening whilst he was quite alert. He also felt he had a tendency to laugh inappropriately at times and this was difficult to inhibit. He felt this behaviour had improved considerably of late. Observations showed only one episode of this behaviour.
10. Assessment of ability to manage financial matters (link with mathematical problems)	Peter was asked to calculate a bank balance. With the use of a calculator, which he would normally use, he was able to complete the task successfully.
	At home, both he and his wife were responsible for looking after their financial affairs. They had a money programme on their computer, which was fairly new and required Peter to learn a new package. Linda tended to read out what had been spent and Peter inputted it into the computer. He occasionally sought reassurance in relation to certain aspects of inputting the information. Peter was keen to start taking on responsibility for managing their money, he was gradually taking on more but at the moment it was important for them to continue doing this together so that Linda was able to monitor his progress.

Table 13.2. (cont.)

Assessment number	Summary of assessment
11. Assessment of mood	Peter maintained a positive, cheerful and apparently calm disposition throughout the testing period. No indication of significant mood disorder.
12. Assessment of upper limb functioning	Peter reported that he had no limitations in functional use of his upper limb, despite being aware that his arm was 'a bit weaker than it was'. The only functional upper limb activity which he was aware of any difficulty in is handwriting, which he reported to be more related to his difficulties in the thought processes associated with writing and the planning of the task, than difficulty with movement of his hand or arm. On observation, his use of a pen was improved, i.e. faster and smoother, when he was asked to copy shapes, rather than to write words. It was further improved when he could see the space into which his pen was moving and when he was asked to produce a shape independently, rather than copying. He had no difficulty lifting his pen from the page or letting go of the pen. His copying of lines improved over time. On examination, Peter had generally low tone throughout his right upper limb, with some mild increased tone in the form of associated reactions, detectable in the hand. He had reduced sensation and reduced proprioception, distally in the hand. Fine movements of the hand were intact, but there was some slowing of rapid alternating movements of opposition of the thumb and fingers. He also had generally low tone throughout his other limbs and trunk and he was mildly ataxic in his movements. However, with regard to function there appeared to be relatively limited impact and he certainly reported no functional restrictions. Peter may benefit from practising at fine movements of the fingers and he had been instructed in these.
13. Assessment of need for further advice re physical fitness training	Peter was attending a fitness gym regularly each week and was confident in the exercises he was performing. To this end he did not require any further advice in this area. He was given advice about one exercise to build up calf muscle strength but did not require firther advice.
14. Assessment of ability on specific functional task (task to be agreed with Peter)	See above – assessment at home. We had nearly completed the Chessington Occupational Therapy Neurological Assessment Battery (COTNAB). Within visual perception (overlapping pictures/figure ground/sequencing) his abilities were within normal limits but he was below average/impaired range on the time taken to complete the tasks.
	Constructional tasks results were the same (2D, 3D, block design). Sensory motor ability: his ability was within normal limits throughout (stereognosis, dexterity, co-ordination) but within the impaired time range. He was unable to complete following

Table 13.2. (cont.)

Assessment number	Summary of assessment
	written instructions – he would read the instructions but not be able to act on this information; when asked to explain why he thought this was he felt that he sometimes could not understand how to actually carry out the tasks and then as the instructions became more complicated and longer he found he was unable to remember the first part of the instructions. When following visual instructions he was able to complete the task with only a minor error and his time just below average. When following verbal instructions his ability was just below average, but his speed within the impaired range made his overall performance within the impaired range. In summary, other than following instructions, Peter's ability was within normal limits for his age group the main problem he had was with his time, i.e. processing speed. Of following instructions, he was most successful following verbal instructions. If he does ever need to follow written instructions they will need to be concise and preferably in his own wording.
15. Assessment of community mobility	He was observed walking from home to the local shops and this was entirely satisfactory. He made appropriate safety judgments.
16. Assessment of dysarthria	Peter had reduced cough and swallow reflexes which affected his eating and drinking. He had particular difficulty drinking thin liquids, e.g. water, and used a strategy of tucking his chin down when drinking in order to protect his airway. This appeared to be an effective strategy at present. He had a shallow pattern of breathing which was occasionally inadequate to support his speech. This required him to take frequent intakes of breath. His voice faded at the end of sentences because of the inadequate breathing pattern. He also demonstrated uncoordinated lip and tongue movements which affected his intelligibility. He also had reduced laryngeal movement which affected his ability to vary volume and pitch in speech. However, he was aware of his speech problems and made attempts to compensate for these, by slowing down and taking time to articulate. During the assessment he also demonstrated an oral dyspraxia, with difficulty imitating movements.

motor speed, visual memory, co-ordination and the ability to learn non-verbal material. During testing, it was noticed that Peter struggled to produce symbols the correct way round although he knew what he should be trying to do. This suggested the possibility of dyspraxia, i.e. an inability to formulate and execute a plan of motor action successfully. Further evidence for such a conclusion was provided by Peter's inability to mime everyday actions (e.g. taking a picture) in the absence of actual stimuli.

Memory

Previous testing using the Wechsler Memory Scale-Revised (WMS-R) had indicated severe problems with logical memory (verbal information presented orally). During the detailed assessment Peter was tested with the Rivermead Behavioural Memory Test (RBMT – Version B), the Doors and People Test and the Warrington Recognition Memory Test.

On the RBMT, Peter obtained a standardized profile score of 17 placing him in the 'Poor Memory' category and a Screening Score of 6 suggesting a 'Moderate' impairment. Specifically, he was completely unable to recall a first and second name presented orally. He also demonstrated, when required to remember a route, a tendency to perform only portions of the required action, suggesting difficulty in sequencing actions. He demonstrated no problem with more 'automatic' information such as 'What year were you born?' but struggled considerably when required to retrieve information requiring some subtle manipulation such as 'How old are you?' This suggested problems with working memory and retrieval.

On the Doors and People Test, Peter demonstrated the following:

1. A visual memory in the average range (above 50th percentile);
2. A poor verbal memory (at the 10th percentile);
3. Poor overall recall (at the 10th percentile);
4. Average overall recognition (exceeding the 50th percentile);
5. A very poor verbal forgetting score (lower than the 5th percentile);
6. An average visual forgetting score (on the 50th percentile).

These observations suggest that Peter's visual memory is far better preserved than his verbal memory. His verbal forgetting score is a function of his inability to memorize the information required in initial encoding. Indeed, he appeared to have great difficulty in encoding verbal information presented orally with visual cues such as a photograph. His ability to recognize verbal information which had been presented earlier was rather better and on a par with his ability to recognize visually presented material. Again, the suggestion is of difficulty with tasks requiring greater conscious control of cognition than more automated responses.

On the Warrington Recognition Memory Test, Peter scored at the 50th percentile for both faces and words.

Informal observations around the Centre during this two-week period showed that Peter was able to remember short pieces of information presented orally, for example he remembered to bring in items for the Memory Group and to ask for information from staff. Thus it may be the volume of information that he finds hard to manage in formal test situations. Alternatively, Peter may have benefited from the repetition of information.

Attention

Peter was assessed using the Test of Everyday Attention (TEA). Although able to complete the Visual Selective Attention subtasks accurately, his performance was slow. This

could have been because this task 'overloaded' his system and/or because he was unable to hold information in working memory in the presence of additional, distracting information. Similarly, while he was able to switch attention (on a counting task), he was slow to do so.

Executive processes

On the Behavioural Assessment of the Dysexecutive Syndrome (BADS) test Peter scored in the impaired range. He performed poorly on a task involving planning and carrying out actions (The Rule Shift Task). He was able to say 'Yes' for a red card and 'No' for a black. However, when he was asked to say 'Yes' if the card was the same colour as the last one and 'No' if it was a different colour, he was both inaccurate and exceedingly slow. He also had difficulties on a task involving planning and carrying out actions (Zoo Map). He made a promising and accurate start but there ensued a long pause and, following this, he seemed unable to cope and appeared to have lost sight of the basic rules. His performance improved considerably when given written instructions which he followed marking each line with a piece of paper. On some other tests such as the RBMT, and the Recognition Memory Test (RMT), it was noted that Peter deviated slightly from verbally presented instructions. This provided further support for the observation that he experienced difficulty sequencing actions and, to some degree, following instructions. Given a stated strategy to follow, his accuracy improved.

Perceptual skills

Although Peter had reported some right visual field loss accompanying his more general right-sided weakness, he failed only one subtest of the Visual Object and Space Perception Battery (progressive silhouettes) suggesting no serious deficits in this area. Nevertheless, in informal observation, Peter was observed to miss information on his right-hand side several times. For example on the Modified Six Elements Test of the BADS, he completely missed the sixth task positioned at the extreme right and, on one occasion, he was noted to collide quite heavily with the door frame on the right-hand side.

During Cognitive Strategy Sessions he was able to accomplish mental rotation tasks so that he could make left–right discriminations with a good degree of accuracy. He was also tested using the Manikin Test on which he made no errors although he was slower to respond when the task involved a greater degree of processing/mental rotation. He explained that he had developed his own strategy for coping with left and right discrimination. This involves sitting with his hands physically separated on his lap. He feels that 'physical separation helps mental separation' and if he were to sit with his hands folded, the task would be considerably harder for him.

Peter was assessed on three of the conventional subtests of the Behavioural Inattention Test, namely Line Crossing, Letter Cancellation and Star Cancellation. He scored full marks in all of these tests and did not therefore demonstrate neglect.

His performance on tasks in which he had to tell the time was very interesting. He could swiftly and accurately read times presented digitally but quickly ran into difficulties with analogue presentation. His errors included:

1. Mixing up the hour and minute hands such that he read 10 past 7 as 25 to 2. When it was suggested that he had answered incorrectly, he offered '10 past 2' and finally '10 past 7'.

2. Errors suggestive of rotational difficulty, for example beginning to set quarter past 10 as 10 past 9 and struggling with the rearrangement for some 40 seconds before correcting himself.
3. Consistent interchanging of 'past the hour' and 'to the hour'.

Peter expressed some surprise that he had muddled hour and minute hands stating that his usual difficulty lay in confusion between 'to' and 'past'. However, he repeated such an error when showed 25 to 11 reading it as '5 to 7'. In addition, he had believed that he could quickly and accurately process o'clock, quarter to and quarter past the hour and half past the hour. Testing, however, suggested that he was not as competent as he had thought with the quarter hours as evidenced by the speed he took and the errors he made. Peter said that if he heard himself make an error he was prompted to correct it but he was not always aware of making an error and he looked for signs from the tester to see if his responses were accurate.

Observation showed that Peter was more likely to succeed if he set the hour before the minute hand. When this was pointed out to him, he had been unaware of it but later agreed that he found such a strategy helpful. There did not appear to be a difference in performance according to whether the right or left side of the clock face was largely involved.

Affect

Peter maintained a positive, cheerful and apparently calm disposition throughout the testing period. The Hospital and Anxiety Depression Scale (HADS) was used to confirm the observation and Peter's verbal report that he was not suffering from symptoms of depression or anxiety. Responses to the Impact of Events Scale indicated that he did not appear to be suffering from post-traumatic stress disorder symptoms relating to his accident. In conversation, Peter was realistic and contained about what happened to him. He was pleased, for example, that the banned and drunk driver who injured him had received a custodial sentence since he considered that the man will, in this way, be kept out of the way of other innocent motorists. He also recognized that this in itself had no direct impact on the problems he was experiencing. He considered that what had happened cannot be changed, to harbour grudges would not be productive and indeed may detract from his rehabilitation.

Peter was relatively accurate in the recognition of six emotions from the Ekman and Friesen Emotion Recognition Task with the exception of 'Fear' where he failed to recognize any of the ten photos depicting this emotion. He usually mistook fear for anger or surprise. He was also noted to have an idiosyncratic startle response.

Summary

In summary, Peter demonstrated considerable difficulties in a number of areas including:

1. General cognitive functioning – in particular retrieval of information and visuo-motor skills.
2. Memory – particularly verbal memory but also working memory.
3. Attention – notably visual selective attention and the speed with which he is able to switch attention.
4. Executive problems – following instructions, planning and carrying out actions.

There appeared to be a dyspraxic component underlying Peter's test performance and presentation as demonstrated in his sequencing actions and conscious control of movement.

Table 13.3. A typical weekly timetable for Peter (NB Each session lasts 30 minutes except for community meeting which lasts for 15 minutes)

	Average no. of sessions per week
Individual sessions	
Speech and language therapy	6
Psychology	4
Occupational therapy	2
Physiotherapy	2
Computer work	2
Group sessions	
Cognitive Group	4
Understanding Brain Injury Group	3
Memory Group	3
Psychological Support Group	2
Weekly schedule	1
Additional sessions	
Daily community meeting	5 (15 mins each meeting)
Working on own	2

Rehabilitation programme

Following the two-week assessment Peter was offered a place on the programme. The plan was for him to spend 10 weeks attending 5 days a week and a further 50 days part-time, spread over several months. Peter and Linda were keen to pursue this.

In March 1998, Peter entered the rehabilitation programme. Like all clients at the Centre, he followed a daily timetable spending some sessions in individual therapy and some in group therapy. His timetable can be seen in Table 13.3.

Peter and Linda agreed the following long-term goals with members of the rehabilitation team. These were slightly different from those considered at the end of the two-week assessment.

Peter will:

1. Increase intelligibility of speech
2. Increase speed of writing
3. Increase speed of reading
4. Spell more accurately
5. Determine whether he can return to his previous job and engage in this – or other activity – part-time
6. Determine whether he can return to driving

7. Return to flying his model helicopter
8. Increase speed in using the computer keyboard
9. Manage his financial affairs effectively
10. Develop a system for remembering and scheduling everyday activities
11. Improve accuracy in telling the time from an analogue clock
12. Be independent in putting in his contact lenses.

For each long-term goal, short-term goals were set with an action plan for each one. For example, one short-term goal to increase writing speed was to improve his performance on a letter-copying task by 20% over the coming week. The action plan for Clare, Peter's speech and language therapist, was to arrange the practice sessions and material. There were several types of goals, some relating to impairments or limitations (e.g. reading and spelling) and others relating to disability and handicap or activities and participation, e.g. managing his finances effectively and remembering everyday activities.

Peter achieved all his goals. We present a brief summary of each of the goals

Goal 1: increase intelligibility of speech

Peter (1) worked on breathing patterns and the effects of breathing on phonation, (2) engaged in exercises to improve strength, co-ordination and speed of tongue and lip movements, (3) identified factors contributing to reduced intelligibility such as noise levels and fatigue and (4) organized his work schedule so that verbally demanding situations were carried out in the mornings when he was less fatigued. The main outcome measures here were ratings from Peter's wife on the intelligibility of his speech and the ease he could be understood by other people.

Goal 2: increase speed of writing

Dyspraxia seemed to be the main cause of Peter's writing difficulties. He seemed unable to know how to copy shapes and letters so exercises in pre-writing skills were devised to increase speed. A baseline was taken of speed and quality of performance on a pre-writing task. Practice exercises were devised for Peter to complete daily. This required him to listen to a tape of verbal instructions asking him to draw a series of horizontal and vertical lines and rows of shapes of increasing complexity. Peter took 24.17 seconds to complete this. After one month, the initial baseline was repeated. Peter's speed increased by 20%. Furthermore, his lines were now smoother, indicating qualitative as well as quantitative change. Another baseline was taken on copying letters. Initially, a letter had to be described to Peter before he could complete the task, e.g. 'draw a straight line down, find the middle' etc. He was encouraged to adopt this strategy himself when engaged in the exercises. Again he carried out the exercises daily and after 2 weeks improved his speed by 20% from a baseline of 24.43 seconds. Other short-term goals were set and achieved. Peter had been unable to sign his name since the accident and this continued until the end of May 1998. Signing his name was one of the short-term goals. He learned to do this and initially took 23 seconds to sign his first and second names. This reduced to 6 seconds by the time of discharge (and 4 seconds at follow-up). Given that Peter had been unable to write cheques since his accident, he needed to contact his bank again to give them a record of his signature. He then began signing cheques once more. This goal was also part of Goal 9 (managing his own financial affairs) and, as we shall see later, Peter learned to manage his financial affairs with the help of his wife.

Goal 3: increase speed of reading

Peter had no difficulty with comprehension. His reading problems were largely to do with speed. Peter engaged in reading passages of different lengths and complexity. His average speed on the passages from the MCLA, increased by 26% over the period of one month but much of the work in reading was carried out under Goal 4.

Goal 4: improve accuracy of spelling

No premorbid spelling difficulties were reported. In the treatment sessions Peter first learned to identify all letters of the alphabet by name and phonic representations. He was next required to identify the difference between consonants and vowels and their characteristics and then to identify how vowel sounds could be represented by different combinations of letters. The next step was to identify the common consonant combinations that cannot be interpreted using phonics. This was followed by learning to recognize phonemes in initial, medial and final positions of words given auditorily and then to increase by 50% his speed of identifying the position of letters in the alphabet. Initially Peter took a mean of 11.23 seconds to determine what came before or after a given letter. Following treatment this decreased to a mean of 5.7 seconds. The next short-term goal was to identify common representations for all vowel sounds. Peter was then required to demonstrate accurate spelling of non-words presented orally using a phonic spelling approach, to accurately spell work-related words presented orally using a phonic spelling method, and to demonstrate increased speed in utilizing the dictionary to check spellings. He achieved all these goals although some of them required a little more time than originally planned. This suggested that we were unrealistic with our deadlines, expecting too much of Peter in the time period allowed. When given additional time, however, he was able to achieve the goals.

Goal 5: identify job tasks and consider whether Peter can return to work

At the beginning of the programme, Peter was assessed on his ability to use a computer system that was critical for his work. Some elements of the system were used frequently in Peter's firm and Peter had used all of these on a regular basis prior to his injury. Peter began working on the most frequently used parts of the system before progressing to less frequently used parts. At baseline he was 60% correct on the frequently used parts and at chance (20% correct) on the less frequently used parts. The techniques of spaced retrieval and errorless learning were employed to teach him how to use the system. By the end of June, Peter could identify the appropriate menus with virtually 100% accuracy. Dealing with telephone calls was another problem area identified (described under Goal 10 below). Peter identified a set of 23 core tasks (including the computer system and telephone calls) required of him at work. He began spending one day a week at work during the part-time phase of the programme. This increased to three days a week. Tasks to be avoided were those involving a great deal of writing as these were too time-consuming. Peter returned to work part-time. Peter's partner valued Peter's knowledge, felt he could 'bounce off ideas' with Peter and appreciated his return to work, though it was clear that Peter would not be able to return to his previous level of responsibility or workload.

Goal 6: return to driving

Peter attended a centre specializing in driving assessment for people with disabilities. The assessment included several brief cognitive tests together with a practical driving assessment on a specially adapted course. He passed the assessment and made a gradual return to independent driving. Although the goal was not pursued at the rehabilitation centre, we facilitated the independent assessment and were prepared to work on short-term goals to enable Peter's return to driving. Fortunately, this was not necessary.

Goal 7: flying model helicopter

Peter bought a helicopter simulator computer programme to practise the skills of helicopter flying. The main problem appeared to be due to his poor visuo-motor skills. He mistook left for right (a difficulty present in other situations such as telling the time) and, consequently, often flew the helicopter in the wrong direction. Initial baseline data indicated that Peter successfully completed all outward journeys but the return journeys were only successful 19% of the time. A training programme was introduced. This included using stickers as prompts both on the screen and on the remote control to indicate left and right. Forty trials were completed with a maximum of ten trials in any one session. A second baseline following the training trials showed that he successfully completed 94% of outward journeys and 82% of return journeys. A further period of training followed with special emphasis on planning when to reduce both the speed and the height of the helicopter. Again there were 40 trials with a maximum of 10 per session. A third baseline showed 100% of outward journeys were successful, together with 87.5% of homeward journeys.

Goal 8: increase speed of using computer keyboard

A computer programme recorded the time Peter took to find each of the keys on the keyboard. Although he did not show a difference between letters on the left and the right of the keyboard, Peter had significant difficulty with certain letters and was slow. Although Peter improved when asked to say aloud the name of the letter he sought, the improvement appeared to be due to practice as there was no significant difference in the rate of change between the baseline condition and the introduction of a verbal strategy [$F(1, 24) = 0.002$, $P > 0.9$]. He continued to practise until a speed plateau was reached.

Peter also practised typing passages. Although still slow, his typing was functional. At work, however, he needed to delegate some of the typing to save time.

Goal 9: manage financial affairs effectively

Peter was seen at home in order to observe his ability to use a home financial management computer package. Peter was able to use this so no further work in this area was regarded as necessary.

Goal 10: developing a system for remembering and scheduling day-to-day activities

Since his accident Peter had relied on his wife for making appointments and had avoided making telephone calls. Although we have no formal data on baseline success it would appear to be close to zero given Peter's avoidance of these tasks.

Peter was provided with an electronic organizer at the beginning of the programme. Use of the organizer and practice in scheduling appointments was demonstrated and practised in the Memory Group. Peter readily adapted to this and from the start made regular and effective use of the organizer. In addition a telephone message pad was introduced as part of his return to work goal (Goal 5). The pad contained specific cues and headings to prompt Peter to ask for necessary information during a telephone call. He also bought a telephone recording device so that he could play back calls if necessary.

Goal 11: improve accuracy of telling the time

Peter's main problems were with (1) the area of the clock containing the numbers 4 to 8 and (2) knowing whether the time was 'past' or 'to' the hour. Baseline data indicated that 65% of his attempts at telling the time were accurate. Peter was taught a strategy to enable him to identify the sides of the clock face. The strategy involved the use of two verbal mnemonics. These were to remember that when the large hand is on the left side of the clock, it represents minutes 'to' the hour and when it is on the right side of the clock it represents minutes 'past' the hour. Peter devised two short sentences to help him remember these facts, 'Two (to) left feet' and 'Walk right past'. His accuracy improved to 100% together with his confidence so that he was now telling the time correctly.

Goal 12: independently manage contact lenses

Dyspraxia appeared to be the major reason for Peter's difficulty with his contact lenses. Before treatment he was unable to put in his contact lenses. A verbal mediation strategy was used in which Peter talked through the specific actions he was trying to perform. This strategy has been reported with other people (see e.g. Wilson, 1999). In addition, stickers were placed on his face, near his eyes, to help guide Peter's hands to the correct position. Within less than five trials, Peter had become independent at managing his contact lenses.

In short, all goals were achieved by discharge. The goals covered a range of practical problems, they were individually tailored to Peter's specific needs and enabled him to be more independent at home as well as returning to work part-time.

Progress since discharge

Peter was seen, interviewed and reassessed in December 1998, March 1999 and August 1999. In addition, he received a neuropsychological assessment from an independent neuropsychologist. Although few of the tests were the same as those we administered, the same pattern of cognitive deficits was identified. On the WAIS-R both his verbal and performance IQs were estimated to be 84 (low average range and almost identical to our findings). On the National Adult Reading Test (NART), the predicted IQ of 95 was identical on both occasions. Peter's recall of stories on the WMS-R was a little higher (11 points for immediate and 8 for delayed recall in 1999 compared with 8 points for immediate and 1 point for delayed recall in 1998). Peter also showed a slight increase in verbal fluency from 11 to 19 although he was still very poor. These results suggest that little spontaneous recovery had occurred in his cognitive abilities so the functional changes were probably due to the rehabilitation programme rather than natural recovery.

Peter and his wife reported that although his speech was not what it was before the accident, they were satisfied with it and said that his speech was readily understood by other

people. Fatigue still affected him so he still arranged meetings or telephone calls during the morning.

Speed of writing achieved during the programme had been maintained but had not increased further apart from his signature which is completed in 4 seconds. The same was true for Peter's reading and spelling. These areas remained at the level achieved during the programme. Peter commented that if he needed to read lengthy documents (something he tried to avoid), he found a quiet environment to do this.

Although Peter remained at work and was confident using the computer software system, he felt that his partner had become the 'driving force' in the company. Peter restricted his work time, did most of his work in the mornings and continued to fatigue easily. As he had recently become a father, child care may have contributed to his fatigue.

Peter was still driving but had changed to an automatic car, did not drive long distances, and shared the driving with his wife. He was also flying his model helicopter but for shorter periods. Before his accident he spent 2–3 hours in this activity whereas he now spent about 1 hour with the model helicopter. He was happy with this.

The keyboard speed was much as it was at the end of the programme, i.e. functional but still slow. Peter had learned to use a new computer software package in addition to the one he worked on at the rehabilitation centre. Peter and his wife managed their financial affairs. They did these together and if Peter undertook something alone, Linda usually checked it. Peter continued to use his electronic organizer for domestic and work arrangements. He also used a mobile telephone with a stored list of numbers so he did not have to remember them.

There were no real problems in telling the time from an analogue clock although when tired he sometimes confused 25 minutes past the hour with 25 minutes to the hour. He could overcome this if he concentrated. He wore a digital watch for day-to-day purposes to make life easier.

Finally, Peter was still able to put in his contact lenses unaided, although as this was a time-consuming task, he usually wore glasses.

Peter was a particularly easy patient to work with. He was self-employed and co-partner in his own firm so we had no problems with employers. He had a strong and close relationship with a supportive wife so we did not have to face issues of problematic family dynamics. He had no mood or emotional disorders, as far as we could tell, and certainly none were identified during the assessment so, once again, we did not have to address these aspects in the rehabilitation programme. Finally, as Peter was financially stable, he and his wife were free from major money problems. Nevertheless, he had significant cognitive and functional problems that were causing considerable problems in everyday life and the rehabilitation programme was able to enable Peter to overcome these and lead a meaningful and productive life.

Reference

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Chapter 14

Lorna: applying models of language, calculation and learning within holistic rehabilitation: from dysphasia and dyscalculia to independent cooking and travel

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Introduction

In Chapter 1 we presented a model of rehabilitation that highlights the range of theories that may be drawn upon to support the identification and development of interventions for the many consequences of brain injury or illness. The case presented here highlights in practice how cognitive neuropsychological *intervention* (as defined by Coltheart (2005)) can be integrated into neuropsychological *rehabilitation*, with a specific emphasis on communication and numeracy. The importance of learning method is also raised both in terms of learning specific skills or information as well as functional generalization.

We describe our work with Lorna as a further example of our interdisciplinary approach, in which team members worked in an integrated way with the client towards shared functional goals. Significantly, Lorna's level of communication was initially considered a potential barrier to her ability to benefit from the groups and participate fully in the therapeutic milieu process. Subsequently these concerns appeared largely unfounded.

Once again a formulation-based approach provided a means of integrating assessment results, developing a collaborative understanding regarding the client's needs and building a basis upon which to address these across the team. The case highlights specific and successful interventions for naming and numeracy difficulties, as well as development of compensatory strategies, together applied to increase participation in meaningful activities as part of the integrated rehabilitation programme.

History of injury

Lorna suffered a brain injury in May 1999 whilst living and working abroad. She sustained a gunshot wound to the head, entry through the left lateral orbital margin and exiting in the

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left parieto-occipital region. An initial CT scan report indicated extensive oedema in the left temporo-parietal regions and brain matter extruded through the wound. She underwent a craniotomy to remove brain tissue and bone fragments and two further operations to drain abscesses under the bone flap. Extensive gliosis was reported in the left temporo-frontal and -parietal lobes. She was believed to be unconscious for approximately two weeks and post-traumatic amnesia was not documented presumably because of significant language impairment in the early stages. A right hemiparesis was documented and Lorna had epilepsy as a consequence of the injury, which was managed through medication. She also sustained a right visual field deficit.

Social history

After initial medical in-patient treatment, Lorna moved back to England to live with her parents. She initially required their full support but her level of independence subsequently improved through provision of local therapy services. Once these services had discharged Lorna both she and her parents wanted further intervention to maximize her potential. Lorna later decided to live with her new partner. At initial assessment she was unemployed and considering seeking voluntary employment. Prior to her injury Lorna held a marketing executive position within a large company, a high-level position, which required a good level of communication and mathematical abilities.

Past assessment

Lorna was assessed by local services on her return to England approximately one year post-injury. They identified difficulties in visuo-spatial functioning, memory, initiation, problem solving, reasoning and receptive and expressive dysphasia (additionally impacting reading and writing). Further neuropsychological testing had not been carried out due to the severity of her dysphasia. Issues with mood management were indicated, including fluctuations in mood, managing frustration and expressing anger. Functional observation suggested dyspraxic errors affecting language and motor skills. An initial right hemiparesis appeared resolved. At this time she was independent for personal care but required supervision, verbal prompting and physical assistance for most other functional tasks.

Detailed assessment

Lorna was assessed at the Oliver Zangwill Centre for Neuropsychological Rehabilitation more than five years after her injury. Following a one-day preliminary assessment, she returned for a detailed assessment, carried out over two weeks. The areas covered in the interdisciplinary assessment were the same as those described in Chapters 13 and 15–21 and included discussion with the client and family members, identifying strengths, weaknesses and potential goals for rehabilitation.

Lorna's self-report of problems and goals

At the preliminary assessment, Lorna was most concerned about her communication difficulties. With support during the detailed assessment, she identified the following goals:

- To use speech and be able to write better
- To find alternative ways to communicate with people
- To make more food

- To have some control over my mood swings
- To learn to relax.

Family interview

Lorna's mother said she would like her daughter to have her own home and live independently, to be able to communicate better, read and write, and at some stage be able to go to work again. Her mother additionally indicated goals to counter mood swings, to enable her daughter to 'calm down', to remember where she leaves things and 'for Lorna to understand that people don't think she is stupid, they don't know she has a communication problem'.

Neuropsychological assessment

Communication difficulties and hemianopia contributed to the pattern of performance on some tests impacting the confidence with which conclusions could be drawn. Lorna engaged well in the assessment process making a good effort to perform as best she could, although at times becoming a little frustrated where she found tasks difficult. Lorna's communication difficulties meant that she required verbal and occasionally visual input to understand the task demands. The results of the cognitive and communication assessment are summarized in Table 14.1.

General cognitive functioning

Three subtests from the Chessington Occupational Therapy Neuropsychological Assessment Battery (COTNAB) were administered (overlapping figures, 2D construction and following visual instructions). Scores reflected slowed time to complete tasks set and below average ability. Results demonstrated ongoing impairments in visual processing of spatial concepts. Qualitatively, Lorna appeared to have perseveration in her motor responses. Uncertainty as to whether this was attributable to difficulty shifting mental set or visual working memory difficulties highlighted the need for further investigation described below.

Memory

Lorna's performance on the Rivermead Behavioural Memory Test-Extended (RBMT-E), indicated above average ability on a test of picture recognition, but poor performance on a test of face recognition. She demonstrated difficulties in remembering the exact route taken around a room both immediately and following a delay (Route Recall), and also had difficulties remembering instructions (Messages).

However, Lorna's performance on tests of visual recognition (Doors) and visual recall (Shapes) was again within the average range.

Attention

On a test of visual selective attention (Map Search), Lorna scored in the average range for the first minute, but her score for the second minute was in the impaired range. This decrease in performance suggested difficulty in sustaining attention over time, which correlated with her performance on the Elevator Counting subtest, which was in the borderline range. On a test of auditory selective attention (Elevator Counting with Distraction), she scored in the average range. On both of these latter subtests (Elevator Counting, Elevator Counting with Distraction), Lorna counted the tones on her fingers and showed how many after each string presented. The use of such a strategy challenged the validity of the results and was therefore interpreted with caution. However, this indicated a strategic approach to problem solving.

Table 14.1. Cognitive and communication assessment scores

Test	Subtest	Score
RBMT-E	Picture recognition	3/4
	Face recognition	1/4
	Route (immediate)	1/4
	Route (delayed)	1/4
	Messages (immediate)	1/4
	Messages (delayed)	0/4
BADS	Rule Shift Cards	1/4
	Key Search	4/4
The Brixton Test	Spatial Anticipation	1 (impaired)
TEA	Map Search 1	7 (low average)
	Map Search 2	2 (impaired)
	Elevator Counting	6 (borderline)
	Elevator Counting with Distraction	7 (low average)
BIT	Star Cancellation	53/54
	Line Bisection	9/9
VOSP	Screening Test	16/20 (pass)
	Incomplete Letters	20/20 (pass)
	Object Decision	19/20 (pass
	Dot Counting	10/10 (pass)
	Position Discrimination	20/20 (pass)
Ekman and Friesen Facial Emotion Recognition	Happiness	10/10 (pass)
	Sadness	7/10 (pass)
	Anger	2/10 (impaired)
	Disgust	7/10 (pass)
	Fear	1/10 (impaired)
	Surprise	7/10 (pass)
Benton Face Recognition	Long form Score	46/54 (pass)
COTNAB (screen including all following instructions subtests)	Visual Perception – Overlapping Figures	A = Borderline T = Below average P = Borderline
PALPA	Spoken word/picture matching	36/40 (4 close semantic errors)
	Spoken word/written matching	(a) 5/15 (4 synonym 4 semantic errors)

Table 14.1. (cont.)

Test	Subtest	Score
		(b) 9/15 (6 unrelated foils)
	Auditory comprehension verbs/Auditory adjectives	23/41& 26/41
	Auditory comprehension locative relations	5/24 (errors mainly reversals)
	Written word/picture matching	23/40 – mixed errors
	Auditory sent/pix matching	31/60 – (Errors: 11 reversal, 8 lexical Sub, 6 lexical vb)
	Written sent/pix matching	25/6 – (7 reversal 9 lexical vb)
	Spoken picture naming	0/20
	Writing names to dictation	0/20
Pyramids/palm trees 3 picture version		45/52
Classification	Constructional ability – 2D Construction	A = Below average
Ability = A		T = Impaired
Time = T		P = Impaired
Overall Performance = P	Ability to follow instructions Visual Instructions	A = Below average T = Impaired P = Impaired

BADS, Behavioural Assessment of the Dysexecutive Syndrome; BIT, Behavioural Inattention Test; COTNAB, Chessington Occupational Therapy Neurological Battery; PALPA, Psycholinguistic Assesments of Language Processing in Aphasia; RBMT-E, Rivermead Behavioural Memory Test-Extended; TEA, Test of Everyday Attention; VOSP, Visual Object and Space Perception; vb, verb.

Lorna's performance on the Star Cancellation and Line Bisection subtests of the Behavioural Inattention Test (BIT) did not indicate neglect or inattention despite her reported frequent bumping into objects on her right side.

Executive functioning (planning and problem solving)

Lorna demonstrated the ability to plan an effective and efficient course of action and to monitor its implementation on the key search subtest from the Behavioural Assessment of the Dysexecutive Syndrome (BADS) battery. This is consistent with her behaviour in other aspects of assessment. However, she performed poorly on the Rule Shift Cards subtest. On examination of the results it became clear that Lorna had used the first rule throughout the second trial. It was not clear whether this was due to misunderstanding the instructions so this result was unclear. She also presented with difficulty in identifying the patterns and scored in the impaired range on the Brixton Spatial Anticipation Test. Whilst comprehension difficulties may have contributed to her performance on these tasks, observations

made during the administration of the COTNAB supported a conclusion of some executive difficulty with formation and shifting of 'mental set'.

Visuo-spatial perception

As mentioned before, Lorna reported consistently bumping into objects on her right side. Whilst passing subtests of the BIT, and being able to voluntarily direct her eyes toward the right, she appeared to have a marked right hemianopia, affecting target detection close to midline on a more rigorous experimental test. Screening assessment using selected items from the Birmingham Object Recognition Battery indicated no difficulty with unusual views matching, visual object decision, or association matching.

Lorna passed all administered subtests of the Visual Object and Space Perception Battery (VOSP) (Shape Detection, Incomplete Letters, Object Decision, Dot Counting), suggesting no gross visuo-spatial difficulties. On copying the Rey Complex Figure, her performance was within the normal range. However, on drawing a clock face from memory, Lorna was observed to complete this task without fully planning the spaces required between digits. Errors were noted on the left-hand side of the clock, with the digit '9' repeated twice, and large spaces between the 6 and 7, and 11 and 12. At this time we thought this reflected either executive difficulties or problems with number knowledge. She was aware of this in the finished result and indicated where the digits should be. A second attempt at the task demonstrated improved performance. She had significant difficulty drawing an aeroplane from memory, taking approximately 10 minutes, and opting to draw a foreshortened view. She was unable to draw a bicycle from memory. She was able to draw a flower and a dog. These findings suggested possible difficulties with representational aspects of her cognition, and that access to structural or semantic information may be impaired.

On the Ekman and Friesen Facial Emotion Recognition Test, her scores were found to be within the normal range for all emotions except anger and fear.

Collectively, in addition to severe anomia, the results of neuropsychological assessment suggested that Lorna's main difficulties were (semantic) memory, establishing and switching mental set, sustained attention and emotion recognition.

Assessment of mood, emotional adjustment and behaviour

Lorna reported that anger was her biggest problem and that she was distressed by her anger and it's impact on other people. She stated that she would like to 'move on' from being angry, find out more about what makes her angry and learn some strategies to manage it. Lorna's anger seemed to be frequently linked with her appraisal of other people's responses, or frustration with difficulties in communication. She also experienced moderate anxiety symptoms, and she described herself as 'a worrier'. These factors may lead to an exacerbation of anger or inaccurate appraisal of other people's reactions, perhaps perpetuated by her facial emotion recognition difficulties. Lorna tended to keep herself busy and cleaned the house in the absence of other tasks, which was understood as one way for her to deal with anxiety/worry. This was considered a coping strategy, consistent with a broader pattern of avoidant coping.

Assessment of language and communication

Lorna reported her communication problems to be mostly about not being able to 'say the word' and then not being able to 'hear' the sounds in a word. Despite these difficulties, she communicated well using a combination of verbal and non-verbal communication.

The pattern of damage resulting from the injury, in conjunction with Lorna's self-report and results of cognitive linguistic assessment indicated both receptive and expressive dysphasia. At the cognitive neuropsychological level, assessment using selected subtests of the Psycholinguistic Assessments of Language Processing in Aphasia (PALPA) (Kay *et al.*, 1992) revealed difficulties with comprehension at a single word level, making semantic errors on spoken word picture matching tests. On written word/picture matching tasks these mild difficulties in semantics were again noted. Errors also occurred on comprehension of verbs, adjectives and locative relations, although the last appeared to be due to reversal difficulties rather than with the comprehension of prepositions. As would be expected, errors were noted on all tasks assessing comprehension at sentence level.

Expressively, Lorna was unable to elicit any automatic speech other than counting one to seven. She reported that she used to be able to count to ten and was uncertain as to why this was no longer possible. Attempts at verbal naming tasks proved unsuccessful although she could communicate what the picture or item was used for. On tests exploring her ability to spell written names of words or to dictation she was able to say how many letters were contained in a given word on several occasions but otherwise her performance was impaired.

Generally, Lorna communicated well despite using very few nouns, utilizing gesture, facial expression, drawing and occasionally spelling out part of a target word.

Within contextual frameworks and in 'real-life' communicative settings she therefore utilized communication skills in the total sense of the word. In summary, Lorna therefore presented with severe deficits in both expressive and receptive language, perpetuated by verbal dyspraxia and auditory processing difficulties.

Assessment of independent living skills

Lorna felt she was functioning well, although remained frustrated by her communication difficulties, which clearly impacted on certain aspects of everyday living, such as dealing with correspondence, reading functional signs, timetables, recipes and asking for specific information. She had a number of strategies currently in use, and it was uncertain whether further intervention could improve her independence, effectiveness or efficiency with selected tasks. Meal preparation was an area of concern and warranted further support, potentially using visual sequencing cards or photographs to aid planning and safety awareness. Reviewing access to community resources, including recreational activities and use of memory strategies was also identified for intervention.

Summary of assessment

The assessment results are depicted in Figure 14.1, the summary of assessment formulation, based on the World Health Organization International Classification of Functioning (WHO-ICF World Health Organization, 2001) framework.

Lorna's rehabilitation programme

Following the two-week assessment Lorna returned for a 24-week intensive rehabilitation programme. During the first 12 weeks, Lorna attended the intensive programme at the Centre four days per week in order to develop greater awareness of her strengths and difficulties, and learn ways of managing these more effectively. This was followed by a 12-week community integration period, involving less time at the Centre, and more time engaged in community activities, in order to help ensure effective generalization of gains. In this chapter we focus

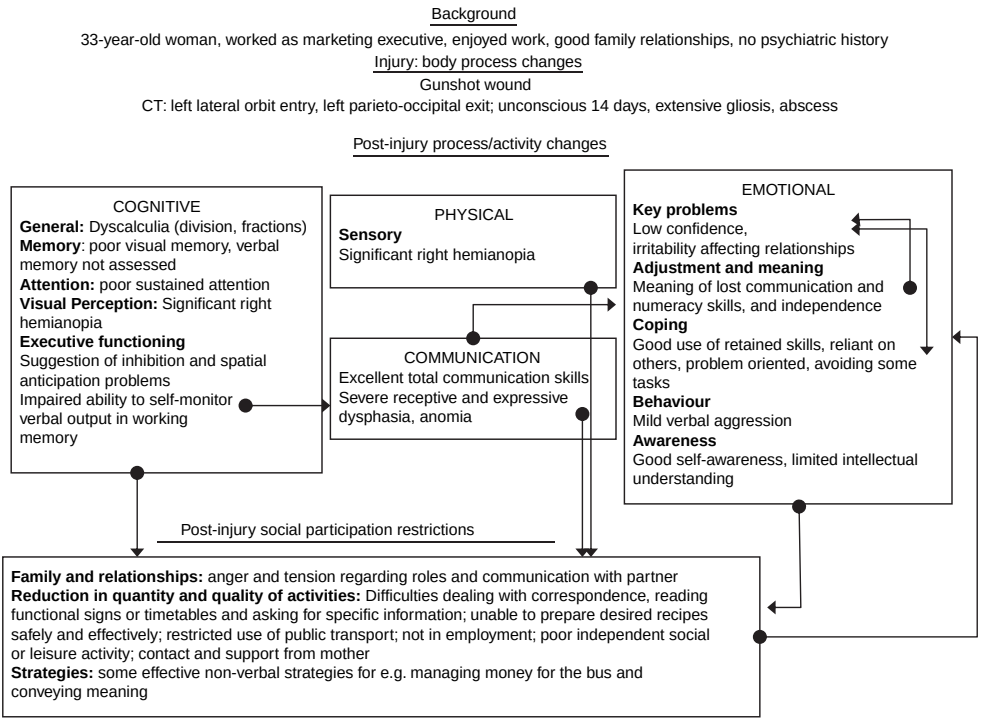
Background
33-year-old woman, worked as marketing executive, enjoyed work, good family relationships, no psychiatric history
Injury: body process changes
Gunshot wound
CT: left lateral orbit entry, left parieto-occipital exit; unconscious 14 days, extensive gliosis, abscess
Post-injury process/activity changes
COGNITIVE
General: Dyscalculia (division, fractions)
Memory: poor visual memory, verbal memory not assessed
Attention: poor sustained attention
Visual Perception: Significant right hemianopia
Executive functioning
Suggestion of inhibition and spatial anticipation problems
Impaired ability to self-monitor verbal output in working memory
PHYSICAL
Sensory
Significant right hemianopia
COMMUNICATION
Excellent total communication skills
Severe receptive and expressive dysphasia, anomia
EMOTIONAL
Key problems
Low confidence, irritability affecting relationships
Adjustment and meaning
Meaning of lost communication and numeracy skills, and independence
Coping
Good use of retained skills, reliant on others, problem oriented, avoiding some tasks
Behaviour
Mild verbal aggression
Awareness
Good self-awareness, limited intellectual understanding
Post-injury social participation restrictions
Family and relationships: anger and tension regarding roles and communication with partner
Reduction in quantity and quality of activities: Difficulties dealing with correspondence, reading functional signs or timetables and asking for specific information; unable to prepare desired recipes safely and effectively; restricted use of public transport; not in employment; poor independent social or leisure activity; contact and support from mother
Strategies: some effective non-verbal strategies for e.g. managing money for the bus and conveying meaning

Figure 14.1 Initial interdisciplinary 'summary of assessment' formulation for Lorna.

specifically on the communication and cognitive impairment work, briefly linking this with functional rehabilitation relating to meal preparation and use of public transport.

Goal setting

Goals were set with Lorna in two broad areas, first relating to social participation or meaningful functional activity (e.g. using public transport), and second concerning underlying skills and knowledge (e.g. cognitive-linguistic ability, understanding and accepting her brain injury). The specific goals set at the outset of the programme were:

1. Lorna will be able to prepare an evening meal of her choice safely and independently using picture cue cards three times a week.
2. Lorna will demonstrate consistent use of an identified planning system to keep track of things she needs to do.
3. Lorna will be able to catch a train from Cambridge to Peterborough independently to visit her family and return using identified strategies.
4. Lorna will extend her expressive language in one or more of the following ways:
   - use of nouns not used prior to the programme
   - use of an assistive communication device
   - use of an augmentative communication system or non-verbal communication.
5. Lorna will report understanding more about her brain injury including: why she can do some things and not others and have information she can refer to in the future.

These long-term goals were subsequently broken down into short-term goals by the team and in collaboration with Lorna. As noted in previous chapters, work towards these goals involved a combination of individual and group sessions involving provision of information, development of skills or strategies to address the specific factors underpinning barriers to achieving these goals. In individual sessions Lorna worked on cognitive rehabilitation for attention and executive problems, communication, and psychological therapy sessions particularly relating to anger. Lorna also attended the Communication, Cognitive, Mood Management, Life Skills, Psychological Support, and Understanding Brain Injury Groups.

In addition to this, Lorna received direct individual support with functional goals relating to work and activities of daily living. These sessions followed the format of initial goal setting, task analysis (breaking the goal into steps or short-term goals), identifying skills, strategies or resources required, matching these against Lorna's understanding of her own injury, then developing strategies to compensate for difficulties in order to achieve short-term goals. These steps were followed in liaison with other professionals in the team such that identification of skills and strategies, and approaches to learning and behaviour change, was done as an interdisciplinary exercise.

In the following sections we describe in detail the rehabilitation of underlying deficits in communication and numeracy, in the context of rehabilitation targeting meaningful functional activity. The aim is to highlight how the initial 'summary of assessment formulation' (Figure 14.1) provided the basis for further specific model-based formulation and hypothesis testing in relation to underlying impairments, the important role of models of learning, and how this work was integrated with work towards meaningful functional goals. Psychological therapy for managing anger and low confidence, understanding brain injury work, development of a memory and planning system, and the details of functional rehabilitation goals around cooking and travel are not described here.

Cognitive neuropsychological rehabilitation of communication and numeracy skills

Communication

As concluded in the assessment, Lorna presented with a long-standing complex communication difficulty. She had been discharged from previous speech and language therapy services and was not expected to make any further progress. However, she remained keen to optimize her communication skills. It was felt that it might be possible to teach Lorna to say a greater range of words, although doubts were expressed regarding her ability to generalize any new learning undertaken to her everyday life. Lorna's intervention was therefore largely experimental, involving alternating and combining different treatment methods and intensity of treatments during her rehabilitation programme. In addition to the intervention we also explored the use of an assistive communication device as an alternative, although Lorna later decided against this idea.

Approaches to aphasia rehabilitation

During the assessment, the cognitive neuropsychological approach had been useful to determine the impairments in cognitive processes. This was largely in relation to plotting areas of difficulty revealed in formal assessment on a model of language processing and being able to hypothesize about the interactions between different processes. However,

in order to address the question of *how* to rehabilitate, it was necessary to look at the literature on current aphasia rehabilitation approaches. The interventions with Lorna were therefore based on existing approaches to aphasia therapy along with some of the principles and techniques embodied in dyspraxia therapy approaches (Rosenbek, 1984). The aphasia approaches of particular significance in the work with Lorna were Constraint Induced Aphasia Therapy (CIAT), a relatively novel approach, and Schuell's more conventional, stimulation approach (Duffy, 1986).

Constraint Induced Aphasia Therapy had been reported initially by Pulvermuller *et al.* (2001) as a therapeutic technique to help improve spoken language in patients with chronic aphasia, in a relatively short period of time. The technique was based on the principles of massed practice, using constraints to force the patient to perform actions usually avoided, and shaping. Meinzer *et al.* (2005) later replicated this study and demonstrated that the outcomes of CIAT could be generalized to everyday life.

In contrast, Schuell's stimulation approach could be considered more conventional as it is better known, and has been implemented by speech and language therapists routinely since its inception. This approach employs intensive auditory stimulation of the impaired symbol system as the primary tool to facilitate and maximize the patient's reorganization and recovery of language. General principles of remediation include intensive auditory stimulation, using adequate stimuli, repetition, eliciting responses, providing opportunity for maximum success, providing feedback about response accuracy, systematic and intensive intervention and grading tasks. All of these principles were implemented in the intervention at some point or another to a greater or lesser degree (Duffy, 1986). Principles of Rosenbek's (1983) verbal therapy techniques for dyspraxia were implemented alongside Schuell's stimulation approach. The intervention evolved over the course of the rehabilitation programme and subsequently broke down into three treatment periods. Each of these are discussed below along with the outcomes after each treatment period. A fundamental principle embedded in each treatment was intensity of treatment. This was consistent with Pulvermuller's CIAT approach and also highlighted in the study by Bhogal *et al.* (2003) in their systematic review of the relationships between intensity of treatment and outcomes.

Treatment 1: Constraint Induced Aphasia Therapy (CIAT)

Constraint Induced Aphasia Therapy was selected on the basis of previous studies mentioned above (Pulvermuller *et al.*, 2001; Meinzer *et al.*, 2005) who used CIAT with chronic aphasic patients and achieved significant improvement in a short period of intensive treatment. The procedure used with Lorna was based on that used in these studies. She received 15 hours of CIAT over an 8-day period, with a 3-day break after the first 4 days receiving a maximum of 2 hours of CIAT per day and an average of 1.8 hours per day. Treatment took the form of a communication game including pairs of cards with photographs of objects distributed among the players (therapist, client and assistant). The objects used included 12 names of objects matched for frequency and familiarity, selected by Lorna for their functional significance in her daily life. The interactions involved making requests and reacting to requests. Screens were set up between players to prevent them from seeing each other's cards and using any non-verbal gestures. Lorna was required to request a particular card by name and respond to a request from another player with a single word response. If she was unable to name the card, a forced alternative was put to her, for example, 'Do you want spoon or bread?', encouraging her to repeat the alternatives as

needed. Modelling and repetition techniques were also used when the incorrect response was given to a request. The use of stereotyped phrases and non-verbal communication was forbidden.

Results 1

Following selection of target words, once intervention started, it became apparent that Lorna was able to say one of the words on the list. We proceeded, however, with using the existing list and carried out the intervention. At the end of the two weeks of CIAT technique, Lorna was able to produce two additional words from the original list. She was also able to produce the first sounds of the other nine words in the list.

Discussion 1

Lorna's response to this initial burst of therapy instilled a level of cautious optimism, both in herself and the therapists. Her performance indicated that she was able to learn new words when presented at the appropriate level of intensity. Feedback received from her partner was achieved through the completion of a weekly monitoring form at the end of the treatment period. This revealed that the newly acquired words were used outside of the treatment sessions and the Centre in her domestic setting, providing some evidence of the beginnings of generalization of newly learned words. The question remained as to whether it was the CIAT technique or the intensity of treatment that affected any change. The logical next step in intervention therefore seemed to be to test out this hypothesis.

Treatment 2: CIAT and conventional therapy

It was agreed therefore that the second phase of intervention would involve targeting two additional sets of words matched for frequency and familiarity. These words were again selected through discussion with Lorna and her partner on the basis of the potential for bringing about functional change in her communicative ability. Eighteen words were selected and divided into two sets. The first set of words was worked on using the CIAT approach as described above. The second set of words was elicited using Schuell's more 'conventional' therapy approach, including word and syllable segmentation, auditory discrimination exercises, articulation drills using consonant and vowel combinations dependent on targeted word and visual, tactile and auditory feedback. Both sets of words were worked on within the same one-hour session once or twice each day, with an equal amount of time spent on each approach during one session. The aim of this treatment was to distinguish more clearly whether an increase in naming ability was independent of the therapy technique used, and rather a result of the intensity of therapy itself.

Results 2

The result after two weeks was that Lorna did not acquire any of the nine words used in the CIAT intervention and was able to learn seven of the nine initial sounds. The result was similar to that obtained using conventional therapy techniques when she was able to learn the initial sounds for all of the nine words.

Discussion 2

The poor performance of both approaches following this second phase led to the conclusion that neither therapy was effective at the level of intensity utilized. This made it difficult to assess the question of whether previous changes in Lorna's naming were due to intensity of input or treatment method. However, given the level of performance following the first phase of intervention, it hinted at the possibility that intensity of treatment may have had

an effect. We felt that this continued to be a significant question, which needed to be explored and clarified further by ascertaining the effectiveness of conventional therapy if delivered at the same intensity as CIAT was in the first phase of treatment. The next stage of intervention therefore involved implementing more conventional methods of therapy as described in treatment phase 2 at the same intensity level as CIAT in the first treatment phase.

Treatment 3: Intensive conventional therapy

In treatment 3, Lorna again received intensive conventional therapy (described above) over a two-week period. Twelve words were again selected by Lorna and her partner and matched for frequency and familiarity with the first set used in the CIAT phase of treatment. She then received 15 hours of conventional therapy over an 8-day period, with a 3-day break after the first 4 days receiving a maximum of 2 hours of conventional therapy per day and an average of 1.8 hours per day. Six words were targeted in the first week, three in the first session and three in the second session each day, and six words in the second week in the same manner. The argument for this was to simulate her exposure to the quantity of new words to what it was for the CIAT in the first treatment phase. Conventional therapy techniques used again included repetition (drills), tactile and visual feedback (mirror), segmenting of words into sounds and syllables, use of symbols as representative of sounds and auditory feedback through audiotapes and minimal pairs. In addition, Lorna was also encouraged to use words at a single word, sentence and conversational level through targeted questioning and sentence completion tasks. Her partner again completed monitoring forms for each week, noting whether these newly acquired words were used in everyday communication.

Results 3

In the final phase of intervention using conventional therapy techniques, Lorna showed dramatic improvements. Prior to starting the intervention Lorna did not know any of the 12 words selected for treatment. At the end of the two-week period she had acquired all of the 12 target words and was able to use these words in response to questions, sentence completion tasks and in short phrases.

Discussion 3

Results suggest that the intense conventional treatment approach proved most successful for Lorna despite the time post-injury. This was consistent with reports in the literature (Poeck *et al.*, 1989). The implications for clinical practice are discussed alongside factors of the holistic rehabilitation approach that impact on performance.

General discussion

Despite having successful outcomes with clients with dysphasia, in Lorna's case, CIAT was not found to be effective for bringing about change in her speech production. Lorna responded best to 'conventional' therapy techniques during the relevant treatment periods, and when this was provided at the same intensity as the CIAT had been in treatment phase 1, the outcome was better than for CIAT. Observations of Lorna and comments she made suggested that the conventional methods were favoured because she was able to participate more in treatment sessions. Conventional treatment required active listening, developing auditory processing skills and production at sound, syllable and word levels. Successes were perhaps more easily identifiable, because even if part of the target word was correctly

produced to Lorna, this signified progress. In the CIAT, successes were harder to achieve, as only the target words were accepted as successes. The severe nature of Lorna's difficulty meant that she needed to work harder to achieve success and inevitably found the task more frustrating. Interactions involved in the CIAT task were also more restricted as only making requests and responding to requests were accepted. This limited the type and quality of the interaction between the client and therapist to some extent. Not being allowed to use non-verbal communication and reducing visual contact further restricted interactions and was contrary to Lorna's natural and preferred communication approach, also a relative strength, which was more of a total communication approach. The CIAT therefore limited her ability to draw on these skills even if only to engage in the treatment process in a more relaxed manner.

It is also possible that Lorna's success following the third treatment phase could in part be attributed to the impact of the rest of the holistic rehabilitation programme within which the communication therapy took place. Although not evaluated formally, it is interesting to reflect on the extent to which improvements in emotional adjustment, increased positive affect and self-confidence may act as a catalyst to bring about change in cognitive functioning targeted by restitution-based rehabilitation. This may also have been a two-way process as Lorna was able to generalize communication successes to other areas of rehabilitation. For example, words targeted in communication interventions were partly selected on the basis of their use in meaningful functional activities, specifically in daily living tasks such as cooking and travelling. This not only consolidated learning, but facilitated generalization of the words learnt from the training context into these functional activities. Generalization of the underlying cognitive linguistic skills to the production of words not targeted in training was not observed, and Lorna was not able to generalize at a sound or syllable level. Repeated formal testing showed that there had not been an overall improvement of expressive or receptive language ability. However, throughout the intervention period, Lorna had demonstrated the ability to learn despite the time post-injury.

At the end of programme, it was therefore felt that further progress was still possible. Lorna was subsequently referred to local services, and in addition to this, and possibly more significantly, Lorna's mother was instructed as to the general principles of the conventional therapy technique. She was able to continue working with Lorna after she had completed her rehabilitation programme. A later review of progress revealed that Lorna had gone on to learn other words significant to her in her everyday life such as family members' names, with her mother's support.

Lorna's numeracy skills

During a cooking assessment, Lorna had been observed to have difficulty understanding fractions of amounts. Several assessments were therefore carried out to investigate Lorna's numeracy skills. The aim of assessment was to determine the extent to which her difficulty with number was attributable to her language difficulties or an acquired deficit in number processing, and to plan rehabilitation accordingly.

Acalculia is a disorder of number processing and calculation skills that may be acquired after a brain injury (Van Harskamp and Cipolotti, 2001). Caporali *et al.* (2000) investigated acalculia in patients with left hemisphere vascular lesions. They found partial recovery could take place in the first few months following stroke, which then reaches a state of stability, or

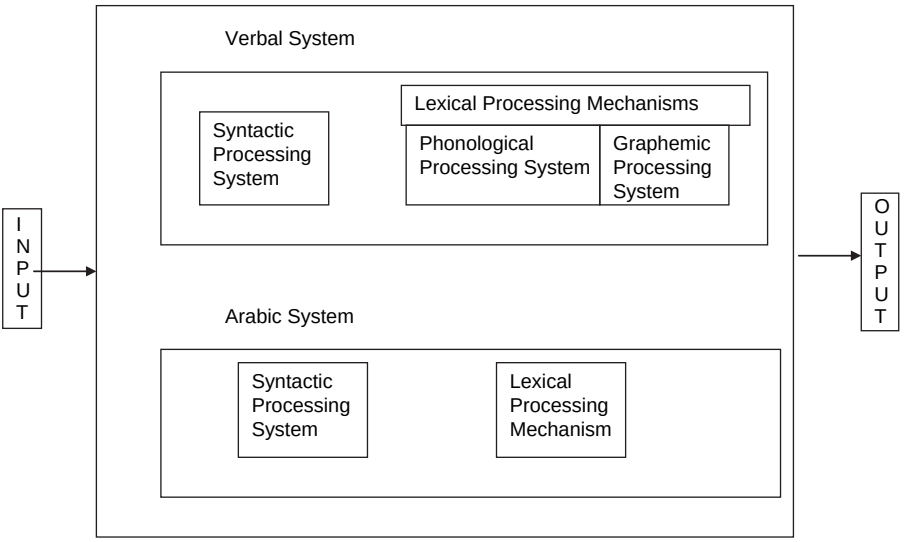

Figure 14.2 Schematic representation of number processes involved in the separate number-comprehension and number production subsystem based on that presented by McCloskey *et al.* (1985, p. 174), with permission from Elsevier © 1985.

declines. This recovery was found not to be dependent upon initial severity. They also report that recovery of calculation disorders correlated with recovery of auditory comprehension. It has been suggested that arithmetic problems are common following a brain injury, as numerical skills are highly sensitive to disruption (Girelli and Seron, 2001). The same authors note that rehabilitation of arithmetical disorders requires detailed diagnosis that is based on theoretical evaluation of the patient's skills. Here we will briefly summarize publications relevant to assessment and rehabilitation.

Background to assessment of acalculia

Models

McCloskey *et al.*'s (1985) model of the cognitive system of number processing and calculation, presented in Figure 14.2 suggests that there are different mechanisms for comprehending and producing numbers. Processing components are distinguished further with different mechanisms processing Arabic numbers from verbal numbers. Lexical processing in the verbal system is broken down further to account for phonological- and graphemic-processing components.

McCloskey *et al.* (1985) describe how, following the comprehension of number, if required, calculation may proceed (see Figure 14.3). They go on to suggest the calculation system has three main components (Figure 14.4). The first is the ability to process the operation symbol (i.e. $+$, $-$, $\times$, $\div$), which allows identification of the calculation to be performed. The second component is the retrieval of basic arithmetic facts–answers to basic arithmetic problems are stored as facts, and therefore require representations within our semantic memory (Hittmair-Delazer *et al.*, 1994). The third component within the calculation system is the ability to execute calculation procedures, such as those required to correctly solve multi-digit problems.

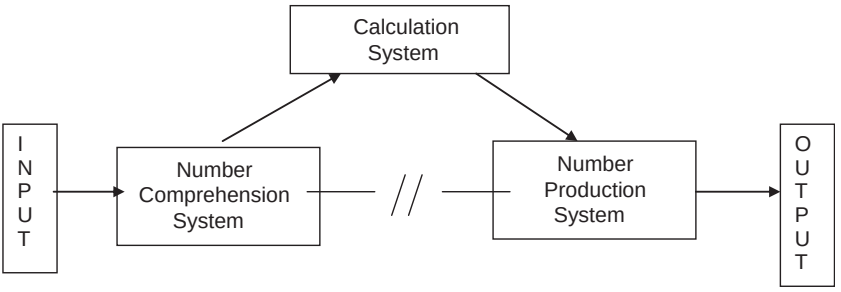

Figure 14.3 Schematic representation of number comprehension, production and calculation subsystems based on McCloskey *et al.* (1985, p. 173), with permission from Elsevier © 1985.

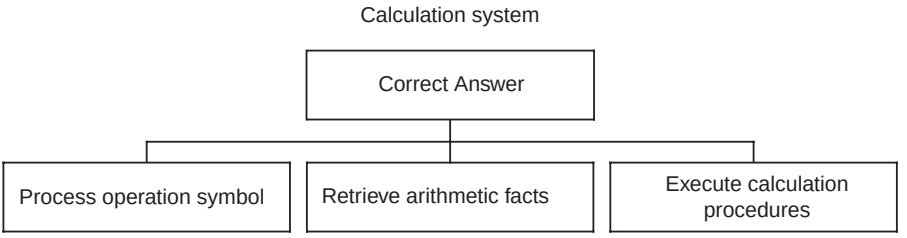

Figure 14.4 Calculation system, based on that of McCloskey *et al.* (1985), with permission from Elsevier © 1985.

Some evidence has been presented to support this model of calculation (McCloskey *et al.*, 1985; Cipolotti and Costello, 1995; Delazer *et al.*, 1999; Sandrini *et al.*, 2003; Basso *et al.*, 2005).

Assessment

Levin (1979) describes an approach to acalculia assessment, based on Benton (1963), that comprises brief tests comparing auditory and written forms of presentation and response. The tests target comprehension of numbers presented in different modes (auditory verbal, or visually presented verbal, Arabic numerals or dots), counting ability and arithmetic calculations. This approach to assessment allows identification of specific abilities that map on to the model of McCloskey *et al.* (1985) presented above, thus allowing clinical assessment in terms of the specific spared and impaired components of the model.

Rehabilitation of acalculia

Despite development of cognitive models of arithmetic, less effort has been directed towards effective rehabilitation of acalculia. Most of the current studies of rehabilitation tend to focus on either numerical transcoding or calculation (Girelli and Seron, 2001). The strategies adopted within rehabilitation typically involve either 'substitution' (using an intact cognitive skill to compensate internally for an impaired skill) or extensive practise and drills to reteach lost knowledge.

Van Harskamp and Cipolotti (2003) suggest that patients presenting with selective impairment for arithmetic fact retrieval should be supported in using back-up strategies involving knowledge of arithmetic fact they have retained. They give the example of using an addition strategy to compensate for impairment in multiplication fact retrieval. Van Harskamp and Cipolotti (2003) also describe a training-based intervention conducted by Deloche *et al.* (1989). The training involved reteaching the steps of explicit transcoding rules with the use of colour cues and vocabulary panels to help the patient convert Arabic numerals into written verbal numerals. The training was found to be successful after training and at seven months follow-up.

Girelli and Seron (2001) present outcome data suggesting that, while patients did not show complete recovery, they did demonstrate benefits from training. They also note that the training effects were retained and were found to spontaneously generalize in some cases. Given that rehabilitation should aim to help clients improve their social participation, the formal generalization of gains into functional situations should not be neglected. To this end, Girelli and Seron (2001) suggest that the remediation of numerical knowledge should attempt to include more ecologically valid tasks, given the difficulties people experience in everyday life following a loss in numerical skills (for example handling money).

We approached our assessment of Lorna's numeracy skills according to the models presented above. The first aim was to make sense of functional difficulties with number in light of the underpinning model of calculation ability and consider appropriate routes for rehabilitation including retraining and compensation approaches as appropriate. Our second aim was to support generalization of these skills through integration into functional goal areas.

Assessment of Lorna's acalculia

Method

As described above, the model of McCloskey *et al.* (1985) was used to guide assessment, and the tasks described by Levin (1979) were used to assess ability within specific aspects of the McCloskey *et al.* model. In relation to number comprehension, Levin's tasks 1–6 (see Table 14.2) covering both auditory and visual presentations were used. The calculation aspect of McCloskey's model highlights three key processes as described in Figure 14.4. Operation symbol processing was assessed through comparison of ability on the four arithmetic operations ($+$, $-$, $\times$, $\div$) within Levin's task 10, with presentation of tasks by both Arabic numerals and using dots, as described by McCloskey and Macaruso (1995). Levin's tasks 9, 11 and 12 were not administered due to Lorna's communication difficulties. Arithmetic fact retrieval was assessed through tasks such as simple arithmetic, recall of tables and counting (simple, backwards and in twos) as described in Levin's tasks 7 and 8. An additional set of tasks (see Table 14.3) was devised to assess fraction comprehension given this type of difficulty was observed functionally and is not included in the approaches of Levin or McCloskey. Fractions were presented in Arabic numerals. Two types of response mode were represented in the tasks: multiple-choice matching of a numerical fraction to a shaded picture, and shading in a fraction of a circle to represent the target numerical fraction.

Throughout assessment, when unable to provide a spoken response, Lorna drew out the number on the palm of her hand or held up her fingers to represent the answer.

Results

Number comprehension and expression

Lorna's performance on the number processing assessment (see Table 14.2) found her to have profound difficulty comprehending numbers presented in auditory form, and marked impairment in the spoken production of numbers, consistent with her communication impairments described earlier. Lorna was however able to copy written numbers, appreciate which of two numbers was the greatest when in visual numeric form and she was able to say numbers from 'one' to 'eight'.

Counting and numerical fact retrieval

Lorna was able to count up to number eight when asked to count upwards starting at one. Lorna was unable to count up in twos or to count backward. Her performance on the counting backwards, counting in twos and calculation tasks also highlighted some deficit in fact retrieval.

Calculation

Lorna was assessed on basic arithmetic calculations presented as Arabic numerals (e.g. '3 + 1') and dots (e.g. '••• + •'). Lorna was found to have no difficulty in simple multiplication presented in either stimulus mode. Lorna made one error in subtraction due to the answer requiring a negative numeral response ('3 − 4 = −1'), and she was unable to attempt this task. On calculations involving addition 3 errors were made out of 12 questions, 2 were within the dot condition and 1 in Arabic numeral condition where the required answer was in the hundreds. In contrast to very mild difficulties with addition, subtraction and multiplication, Lorna demonstrated a particular difficulty with division questions, correctly answering two of ten problems presented as dots and numerals.

Fraction knowledge

Lorna was observed to have great difficulty with the fraction assessment, which required her to shade in the written fractions or matching a numerical fraction to a shaded picture. Table 14.3 shows her performance for both conditions, 'colour in' and 'fraction matching'.

Discussion

From the findings of our initial assessment of Lorna's number processing ability, we can say that Lorna had some deficit in processing auditory numbers consistent with her communication difficulties. Lorna's performance suggested she still possessed a degree of number knowledge, which was made evident if questions were presented in a modality that accommodated for her language deficits (e.g. copy numbers, appreciate which of two numbers was greater when presented visually).

Lorna had deficits in fact retrieval evident on some assessments. Despite language difficulties, Lorna was able to count up to eight, although she was unable to count up in twos or backwards within this numerical range. This may be suggestive of a deficit in conceptual knowledge of numbers as backward counting and counting in twos should be represented as semantic knowledge.

Within her calculation skills, a selective impairment for simple division calculations was found, with some mild difficulty in other areas.

Lorna demonstrated particular difficulty on the fraction assessment. Lorna could only correctly and reliably answer questions depicting either a whole, half, or quarter. Lorna

scored slightly better on a task which gave multiple-choice answers; however, her performance was variable.

From the assessment Lorna's difficulty with number can be mapped on to the number processing model by McCloskey *et al.* (1985): first there is a clear discrepancy between Arabic and auditory-verbal number comprehension and expression. Specifically, Lorna had difficulty producing and understanding spoken numbers (phonological processing) consistent with her communication difficulties.

Within the model of calculation, Lorna appeared to have difficulty with some aspects of fact retrieval. Lorna displayed a selective impairment for division calculations and fractions. Other calculation functions were considered intact.

Rehabilitation of Lorna's specific numeracy and calculation deficits

Lorna received speech therapy to increase her spoken production of numbers, as described earlier in this chapter. Regarding her calculation deficit, Lorna had a goal towards regaining her understanding of fractions and feeling more confident with numbers. The potential application of any skills gained in functional situations relating to cooking and use of public transport was also considered, and as such the work described here contributed to the plans of action under these broader functional goal areas.

Method

A single case pre/post-intervention design was used to evaluate the efficacy of the training programme. Given the identification of number processing deficits relating to calculation (division), and the functional relevance of understanding fractions, especially to cooking, training was focused on regaining knowledge of basic fractions. Thought was also given to methods of learning, and following from Girelli and Seron's (2001) recommendations an errorless approach was adopted. However, given that increased encoding or processing may increase memorability for target information, the errorless condition of learning needed to involve some effortful processing within the training task.

The pre- and post- intervention assessments consisted of the repeat assessment of skills described above.

In the training intervention, Lorna was presented with numerical fractions and a shape divided with a grid allowing visual depiction of fractions (e.g. a square divided into four cells). Lorna was shown which shaded picture matched the target. In order to enhance learning of this information through effortful errorless processing, Lorna was instructed to shade in the appropriate area of the shape to match against the numerical target. After some sessions of this approach it became apparent that Lorna was becoming able to spontaneously match the shaded picture to the written fraction. She asked if the meaning of the numbers in the written fraction could be explained, so rehabilitation sessions then focused on explaining the meaning of the numerator and the denominator. The process of these sessions allowed Lorna to divide up different shapes according to the denominator and shade in the amount stated by the numerator. It became apparent early in these sessions that Lorna was beginning to regain her confidence in numbers, she enjoyed the training, and asked for more challenging tasks to be set.

Results

At the end of the training programme Lorna's fraction knowledge, number processing, and calculation were re-assessed, and these data are presented in Tables 14.2 and 14.3.

Lorna was able to recognize fractions including halves, thirds, quarters, fifths, sixths, eighths and tenths. On this occasion Lorna was also presented with simple fraction calculations. Lorna was able to solve addition and subtraction questions when fractions were presented as pictorial representations; however, she was unable to respond correctly if questions were in Arabic numeral form (Table 14.3).

Lorna's performance on fraction assessment prior to and following training Lorna's ability to perform simple arithmetic calculations had improved, when tested again. The result strongly suggests that the training Lorna received in recognizing, understanding and calculating fractions had generalized to her ability to use division. Improvements in number processing were also evident, suggesting improvement in number comprehension, or retrieval of numerical facts, or relearning. It is possible that improvements in these areas may have also arisen from the communication rehabilitation she received.

Functionally, towards the end of the training programme, Lorna was observed during her cooking sessions to have improved in saying the words 'half' and 'quarter' whilst cutting an omelette and a pizza, demonstrating some generalization of learning of these concepts, although this was not assessed formally.

Discussion

Compared to the results from the initial assessment an improvement appears to have been made in number processing (comprehension and production). Our specific analyses highlight significant improvements in calculation ability from pre- to post-training.

Some improvements appear to have been made in relation to Lorna's number processing, specifically phonological processing of number. Within the calculation model, an improvement was noted in fact retrieval and counting, as was an improvement for division calculations.

It is likely the changes in number comprehension and production are related to the communication intervention that was specifically concerned with rehabilitation of these skills, in addition to self-monitoring of verbal input and output. Improvements in calculation ability were largely associated with improvements in division. This finding is of interest as division knowledge was not the direct focus of intervention, although understanding of division may have been improved through rehabilitation of fraction knowledge and development of understanding of the numerator and denominator.

Lorna's ability to process spoken number appeared to have improved as shown in her ability to recognize which of two numbers is greater, and writing numbers to dictation. Her fact retrieval on a task of counting backward from 20 and counting up in twos, which previously she was unable to attempt, improved greatly. As this area was not the focus of either the training of fractions, or of her communication deficits it is difficult to account for this finding. It is possible that Lorna did not attempt the task at initial assessment due to low confidence, and that this change in confidence may underlie what appears to be a change in numeracy skills.

Conclusion

Lorna presented with specific deficits in numeracy that were assessed systematically and test results were interpreted in line with a model. This allowed identification of difficulties with the function of division. Clinical and functional observation highlighted how this difficulty was evident in understanding and calculating amounts (fractions or

proportions) when cooking. The model suggested a deficit in knowledge of fractions (beyond simpler fractions such as a half) and deficits in knowledge of rules for fraction calculations (relevant to both division and complex fraction comprehension). In addition to the model of number processing and calculation, models of learning were also required for rehabilitation. This allowed identification of a specific area for clinical intervention (fractions and divisions), a target for intervention (semantic knowledge of fractions and calculation methods) and a method (errorless yet effortful tasks). Systematic evaluation of the training was carried out and the results indicate significant improvements in the target of intervention (fraction knowledge), and generalization of this ability to the function of division.

Lorna was over six years post-injury yet the approach adopted here combining errorless and effortful learning allowed lost knowledge to be regained. Functional generalization was not rigorously assessed. However, improved ability to manage amounts was observed in cooking. Lorna had already adopted compensatory strategies for managing money when shopping and using public transport, so generalization of this work was not extended into these functional goal areas. Of significance was the positive effect of this work on Lorna's confidence and self-esteem. Lorna herself reported how pleased she was with having regained her concept of fractions: 'This is a big wow, I feel like my body is waking up, like it has been in sleep time.'

Functional outcomes

Lorna also collaborated with the team in developing and applying skills towards cooking specific dishes and relearning to use the train to travel locally to visit family and attend rehabilitation independently. The communication and numeracy skills developed as described above were specifically drawn upon where necessary to aid performance in community activities. However, additional approaches such as task analysis, developing skills through graded hierarchy of difficulty, semantic relearning of information (e.g. how to catch trains) and problem solving (e.g. what to do if the train is cancelled) all contributed to this work. Furthermore, practical compensatory strategies (such as cue cards for recipes, and carrying an old ticket for the train journey she intends to take in order to purchase the ticket without relying on verbal communication) were important in facilitating functional gains. In addition to the outcomes reported above regarding changes in performance with regard to specific deficits, changes in functional performance were also evaluated through goal attainment, and completion of self- and carer-rated questionnaires.

Goal attainment

At the end of the programme Lorna had partially achieved her long-term goal of being able to prepare an evening meal of her choice three times a week. This was partially due to social circumstances and negotiation of changes of role as she reported that her partner continues to do the majority of cooking within the home environment, but that her confidence with making food has significantly improved. Lorna fully achieved her long-term goal of being able to catch the train to visit her family independently. She appeared confident in her ability to complete this task and was able to generalize this learning to additional routes. Her self-rated performance scores on the Canadian Occupational Performance Measure had also improved at the end of the programme.

Table 14.2. Results of assessment of number processing pre- and post- training (following Levin's (1979) method based on Benton (1963), with modifications made to account for Lorna's communication difficulties)

Task	Stimuli	Pre-training		Post-training	
Number processing					
1. Appreciate which of two numbers is greatest	Visual – numeral	6/6		6/6	
2. Appreciate which of two numbers is greatest	Auditory	0/6		4/6	
3. Reading numbers aloud	Visual – numeral	8/10		10/10	
4. Point to written numbers from spoken presentation	Auditory	3/9		5/9	
5. Write numbers to dictation	Auditory	2		13	
6. Copy	Visual – numeral	12/12		12/12	
Counting ability/ fact retrieval					
7. Count from 1–20	Verbal instruction	8/20		10/20	
Count backwards	Verbal instruction	0/20		20/20	
Count up in twos	Verbal instruction	0/10		10/10	
8. Count strings of dots	Visual (Dots)	8/12		10/12	
Calculation/operations					
9. Oral arithmetic calculation	Verbal	Not administered			
10. Written arithmetic calculation	Visual – numeral		Total		Total
Addition	Numeral	6/7		7/7	
	Dots	3/5	9/12	5/5	12/12
Subtraction	Numeral	4/5		5/6	
	Dots	5/5	10/11	5/5	10/11
Multiplication	Numeral	6/6		6/6	
	Dots	4/4	10/10	4/4	10/10
Division	Numeral	1/6		5/6	
	Dots	1/4	2/10	4/4	9/10
Total			31/43		41/43
11. Arithmetic reasoning ability		Not administered			
12. Immediate memory for calculation					

Table 14.3. Lorna's performance on fraction assessment prior to and following training

Target fraction	Response mode	Pre-training	Post-training
	Colour in		
1		✓	✓
½		✓	✓
⅓		×	✓
¼		✓	✓
⅕		×	✓
⅔		×	✓
	Match picture to fraction		
1/1		✓	✓
½		✓	✓
¼		×	✓
⅓		✓	✓
2/5		*	✓
4/6		*	✓
4/10		*	✓
2/8		*	✓
Fraction calculations	**Write or draw**		
½ + ½		*	✓
¼ + ¼		*	✓
⅓ + ⅔		*	✓
1 − ¼		*	✓
½ − ¼		*	✓
¾ − ¼		*	×
6/8 − 2/8		*	×

*=No result as Lorna was unable to complete testing due to the level of difficulty.

Summary and conclusions

This chapter describes the rehabilitation of Lorna, a woman six years post-injury, who presented with a marked degree of dysphasia, physical, cognitive and emotional problems, all of which were targeted in her rehabilitation programme in keeping with the holistic approach followed at the Oliver Zangwill Centre. The interdisciplinary programme for Lorna illustrates how models of cognitive functioning, in particular models of calculation, language and learning, acted as starting points in association with other models and approaches to produce strategies and develop skills aimed directly at the functional consequences of Lorna's brain injury.

Following a detailed assessment at process, activity, social participation and contextual levels, in the light of these models, Lorna and the team set goals to drive her rehabilitation. Attainment of goals is one of the main measures used at the Centre to evaluate outcome and five specific goals were set to be achieved by the end of the programme.

Lorna's significant communication problems were identified using a model of language and two treatment strategies with some supportive evidence for possible efficacy were employed and compared. These were Constraint Induced Aphasia Therapy (CIAT) and a more conventional therapy following a targeted practice design. The second approach was more successful when implemented at a high level of intensity. Furthermore, the new words learned were employed in real-life settings such as cooking and travelling by train. Lorna's mother was instructed in the general principles of the communication programme and was able to help Lorna after discharge from the programme to ensure that progress continued. The speech and language therapy was just one component of the holistic programme Lorna was engaged in. As a result of specific psychotherapeutic intervention as well as the general effects of improved functional independence, her confidence and self-esteem improved.

The treatment for Lorna's calculation difficulties is a prime illustration of a cognitive model being used to plan treatment. Following on from knowledge gained from research in the area, a single case design was used to evaluate the efficacy of treatment and she learned to recognize fractions. This knowledge generalized to a significant improvement with calculations involving division, a calculation that had not been taught directly.

Functionally, then, this very impaired woman who was six years post-injury (when some purchasers are reluctant to even consider rehabilitation) achieved most of her goals. Assessment and treatment, within a context of knowledge provided by models and research studies, enlisted a number of different approaches as recommended by Wilson (2002) and focused on real-life difficulties. The cognitive background or framework, combined with appropriate strategies, contributed towards a rehabilitation success.

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Chapter 15

Caroline: treating post-traumatic stress disorder after traumatic brain injury

Jonathan J. Evans and W. Huw Williams

Introduction

Most people who suffer serious traumatic brain injury (TBI) have a period of loss of consciousness and post-traumatic amnesia that typically means that they do not recall the moment of injury itself. They may also have a gap in memory stretching from some time prior to injury to some time after the injury. Therefore despite going through the traumatic experience of a motor vehicle accident or assault or fall the individual may have no recollection of the incident itself. Post-traumatic stress disorder (PTSD) is a mood disorder characterized by re-experiencing (flashbacks, nightmares), avoidance and arousal symptoms (e.g. hypervigilance) in relation to having experienced, witnessed or been confronted by an event involving death or serious injury that results in feelings of fear, helplessness or horror (American Psychiatric Association, 2000). In the context of amnesia for the traumatic event, the question as to whether PTSD can occur after TBI, has been the subject of some debate (Sbordone and Liter 1995; Bryant *et al.* 2000; Williams *et al.* 2002; Sumpter and McMillan 2006). However, it is generally accepted now that, through various different mechanisms, PTSD can occur after TBI (Bryant, 2001). Some people who suffer a closed head injury have partial recall of the incident (Creamer *et al.* 2005) with some experiencing specific 'islands' of memory for traumatic events (King, 1997). For those who suffer open head injuries (where the skull is penetrated, for example with gunshot or sharp object wounds), there may be quite severe injury, but no loss of consciousness, at least initially. In this case there may be full recollection of the injury incident itself. In this chapter we describe the rehabilitation programme undertaken with Caroline, who developed severe PTSD following an open head injury arising from an assault. Details of this case have previously been described in a paper by Williams *et al.* (2003).

History of injury

Prior to her injury Caroline was an artist and worked in the area of art education. At the age of 24, Caroline was assaulted whilst travelling on a train. She was stabbed in the head with a large knife that penetrated her skull from the right parietal region through to the front of

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her skull. During the course of this experience she did not lose consciousness and was able to report a detailed account of the incident:

> There was a lot of people on [the train]. People got off, and I was alone. I [was] engrossed in book…I saw a man go past…he smiled and went to the next carriage. He came back two minutes later…[and walked past], after 30 seconds I felt pain in my head and weight as if the carriage had fallen on to me, I got up and realized that something terrible had happened…I went into the next carriage…another man told me to sit down, and that he would get help, and told me to stay still. I put my hand up and felt the knife. I asked if I was to die. He said no, and he'll get help. At the next stop an ambulance arrived and took me to hospital.

Caroline underwent surgery to have the knife removed. The track of the knife through the brain had missed major blood vessels and key brainstem areas. A CT scan demonstrated subcortical white matter infarction in the right temporo-parietal region and enlargement of the right lateral ventricle. She was discharged home two weeks after surgery described at the time as having, 'a left homonymous hemianopia, an optokinetic nystagmus to the right (localizing the lesion to the right parietal cortex), substantial anxiety, and no other neurological abnormality' (Hart and Casey, 1997).

Caroline was referred to the Oliver Zangwill Centre for Neuropsychological Rehabilitation two years later. Caroline had been seen on a monthly basis by a psychiatrist, once every 2–3 weeks by a clinical psychologist and weekly by an occupational therapist. She had been prescribed antidepressant and sedating medication, having developed severe PTSD. She had not been able to return to work. At initial assessment Caroline reported feeling depressed, in fear of other people, lonely and isolated from friends and family. She reported difficulties with concentration, memory and organization. She said she felt angry, but kept her anger inside, and also felt irritable and impatient. She felt extreme tiredness. She felt tense and restless. She had trouble sleeping, with difficulty falling off to sleep and waking early. She had intrusive thoughts and images and nightmares of a violent nature at least once a week and sometimes more often. She lacked confidence. She reported that she found it hard to trust others. She had problems with her eyesight (left homonymous hemianopia), which affected her reading and led to her walking into things.

Neuropsychological assessment

Caroline underwent a neuropsychological assessment as part of her detailed assessment for the neuropsychological rehabilitation programme. This revealed that although she was not suffering severe cognitive impairment there was evidence of reduced speed of information processing, shown on the Speed and Capacity of Language Processing Test (Baddeley *et al.*, 1992). There was evidence of some attention/concentration difficulties and in particular coping with distraction and switching between tasks, shown on the Test of Everyday Attention (Robertson *et al.*, 1994). She had mild difficulties with memory, shown on the Rivermead Behavioural Memory Test (Wilson *et al.*, 1985). Her general intellectual ability, demonstrated through her performance on the Wechsler Adult Intelligence-Scale-Revised (WAIS-R) (Weschler, 1981), was intact and consistent with estimates of premorbid ability. It was considered likely that mood difficulties were impacting on cognitive performance, but that there was nevertheless evidence of some cognitive impairment arising from the neurological injury.

Mood assessment

Prior to her assault Caroline had no history of psychiatric or psychological problems. At assessment, Caroline reported symptoms of PTSD and hence the Clinician Administered Post Traumatic Stress Scale (CAPS; Turner and Lee, 1998) was used. The CAPS provides a comprehensive scaling of the frequency and intensity of each of the key symptom areas associated with PTSD. Caroline reported significant hyperarousal and panic attacks, feeling panicky with heart racing, nausea, being hot and cold on a daily basis. She often felt claustrophobic and had elevated social fears – she was hypervigilant in relation to danger to herself and had fears relating to harm coming to others. She reported intrusive images, particularly triggered by being in enclosed spaces, travelling or being in crowds. The intrusive images were of people being stabbed, which were described as feeling real at the time they were experienced. Caroline reported sleeping for only 3–4 hours per night, with frequent waking due to nightmares and significant difficulty in returning to sleep. She had periods of suicidal ideation. Caroline avoided situations that reminded her of her trauma. She had not travelled by train since her injury. She had travelled by bus, but experienced significant distress even on short journeys. She avoided busy places and so did not go to restaurants or the cinema, and only went to the shops at quiet times.

Caroline had not returned to any occupational activities. She had supportive contact with her family and a set of close friends.

Formulation

As a result of experiencing a traumatic assault that was out of her ordinary experience and involved a threat to her life, Caroline was suffering severe PTSD, with intrusions (flashbacks, intrusive images and nightmares) and avoidance (of reminders of the injury). She had some cognitive impairment including some reduction in speed of information processing, attention/concentration and memory. It was hypothesized that Caroline's mood disorder contributed to cognitive difficulties. For example it seemed likely that intrusive thoughts/images and hypervigilance to perceived threat would further affect concentration and also memory and planning skills. With regard to the functional consequences of her difficulties, it was concluded the PTSD was primarily responsible for limitations in social, leisure, domestic and occupational activities, but that brain injury-related problems with speed of information processing, attention and memory would also make addressing these problems more difficult.

Caroline attended the rehabilitation programme for an intensive phase of 14 weeks (5 days per week) followed by a period of 20 weeks attending on a gradually reducing basis.

Rehabilitation goals

During the course of the detailed assessment and the early phase of Caroline's rehabilitation programme a set of goals for the programme was established. In the broadest terms, Caroline's aims were to feel less distressed and in control, to experience fewer intrusive images and nightmares, to be able to go to, and feel confident in, places she was avoiding and to return to her art work. Based on these aims, specific goals were established with Caroline focused in part on management of specific symptoms of PTSD

and in part on functional activities of daily living along with social and vocational activities. The goals were:

1. To demonstrate an accurate understanding of the consequences of her brain injury, their impact on her daily life and the strategies that she can use to manage them.
2. To reduce the intensity of daily intrusive thoughts/images (from moderate to mild using the CAPS rating).
3. To reduce the frequency of unpleasant dreams (from severe to moderate using the CAPS rating).
4. To rate herself as comfortable in more than 70% of interactions in personal relationships.
5. To rate herself as being hopeful more than 50% of the time.
6. To use a memory and planning system to carry out independent living activities successfully on at least 80% of occasions.
7. To use strategies to sustain attention during everyday activities in order to concentrate on them successfully on more than 70% of occasions.
8. To be able to comfortably engage in identified activities which she previously avoided including:
   (a) To travel independently by train on at least one short familiar route.
   (b) To go shopping at a moderately busy time.
   (c) To feel comfortable in an unfamiliar pub or restaurant.
   (d) To feel comfortable in a cinema.
9. To be engaged in a physical leisure activity on a weekly basis.
10. To undertake a vocationally related course and have a clearly documented plan for returning to paid employment.

Rehabilitation programme and specific interventions

The rehabilitation programme with Caroline could be seen to have three components. The first component was to understand more about her brain injury and its consequences in terms of both cognitive impairments and PTSD. The second component involved developing strategies for managing both the cognitive and emotional consequences of her injury. The third component involved Caroline applying these strategies in everyday situations in order to achieve her personal practical goals.

To develop her understanding of the consequences of her injury, Caroline attended the Understanding Brain Injury Group and worked with her individual programme co-ordinator to complete a portfolio relating to her brain injury. With support, she was able to review reports and scans to understand (and document in her own words) the nature of her original injury as well as the consequences. She was able to use the portfolio to record the work she was doing in relation to her other specific goals such as managing memory, attention and emotional difficulties.

The central focus on Caroline's programme was on managing her PTSD. A cognitive behaviour therapy (CBT) approach (see Harvey *et al.*, 2003) was used. Cognitive behaviour therapy interventions for PTSD have four main elements. These are psychoeducation, exposure, cognitive restructuring and anxiety management training. Each of these elements was incorporated into Caroline's broader neuropsychological rehabilitation programme.

The work Caroline did to understand the consequences of her injury involved re-exposure to the traumatic event through talking about the incident and its effects on her. This was further elaborated in the work she did to develop strategies for managing both cognitive and mood problems. Caroline attended the Cognitive Group, Mood Management Group and Psychological Support Group.

In individual sessions with a clinical psychologist, Caroline worked on developing strategies for coping with intrusive images. Caroline learned breathing-based relaxation strategies to manage physiological arousal. She also worked on manipulating intrusive images in her mind in order to reduce the frightening nature of these images and to gain a sense of control over them. For example she had images of her attacker attacking both herself and others. She developed a strategy of making her image of the man smaller and turning the image into a cartoon-like figure. Similarly, she had images of multiple knives in her head and she was able to change this to an image of her calmly pulling the knives out of her head. Caroline was also provided with sessions to talk about her fears regarding her own safety and that of her family and others. She tended to be over-inclusive for threat of harm coming to family members in particular and was supported in testing the evidence for and against this thinking style.

Caroline had identified that she found it difficult to concentrate in several situations. In particular she noted that she had difficulties if she tried to read books or newspapers and found it hard to take part in conversations when there was a group of people present. One of the main things affecting her concentration was being distracted by anxious thoughts and images. The work on managing this problem described earlier was therefore more generally relevant in improving her ability to concentrate. Similarly, techniques for managing fatigue (e.g. pacing herself more effectively by using her planning system described later) had a positive effect on her ability to concentrate. Furthermore, as her mood improved Caroline reported that she felt able to be 'less inward looking' and take more of an interest in things, which improved her ability to concentrate on things like newspapers and novels. In relation to dealing with situations with conversations in group situations a set of strategies was developed which were:

1. Be 'present' – i.e. attend to what's going on.
2. Observe and engage in conversation when ready.
3. Use self-talk:

    'I don't need to listen to *every* word'
    'Breathe and relax'
    'Be confident'

4. Pick one person and talk one-to-one.
5. Take breaks.
6. Ask for things to be repeated.
7. Ask questions when I want the focus away from myself.
8. Practise putting worry thoughts to one side.

Over time, Caroline reported using these strategies in a variety of social situations and felt her ability to cope in these situations improved a little. Nevertheless she was aware of continuing problems and in particular coping with background noise and keeping up with conversations that move rapidly.

Caroline also learned to use a personal organizer system in order to support her memory and planning. This involved use of a diary (for events), to-do list and planning frameworks. The latter involved listing the tasks she needed to do for common activities to help guide her through detailed planning for activities and provided a structure to follow when completing the activities. Caroline used the planning frameworks to support her in completing specific tasks that formed part of the third phase of her programme. This involved her working through a hierarchy of activities leading towards completing the tasks that comprised her functional programme goals (e.g. going shopping at a moderately busy time, going to a pub or restaurant, travelling on a train journey).

For example in relation to the goal of travelling on a train journey on her own, a hierarchy was developed that included:

1. Accompanied trip on bus from hospital to town.
2. Accompanied at a distance on bus to town.
3. Alone on bus to town.
4. Alone on longer bus journey.
5. Visit to train station – this involved collecting train timetable information.
6. Sit in train carriage whilst train in station – as some trains were stationary at the platform for a considerable period of time it was possible to at first simply walk through a carriage and then to sit briefly on the train.
7. Accompanied trip on train one stop (5 minutes).
8. Independent trip on train one stop (5 minutes).
9. Independent trip on train (25 minutes).

As she worked through this hierarchy Caroline was supported in vivo by a person accompanying her to apply breathing-based relaxation techniques to manage physiological arousal and the image management techniques described above. Similar hierarchies were established for going shopping, to the cinema etc. Caroline used her planning checklist to help her plan the timing of the journeys, routes and costs. For example in relation to going shopping she would write out her plan of what to get, which shops she may need to visit, when and where she could take a break, the amount of money she may require and travel arrangements, including a number for a taxi. She kept the checklist in her filofax, to have the written plan to refer to if she became anxious while out. She reported examples of situations when her plan had been disrupted for some reason, but by taking time out to review her plan she was able to manage her anxiety, revise her plan and complete her intended tasks. Over time she reduced the amount to which she needed to refer to the plan as her self-confidence increased.

Caroline had the goal of returning to her art and as she became more confident in her ability to tolerate travelling and being in moderately busy places, Caroline was able to start attending two art classes. Again she used her personal organizer and planning frameworks to support her getting to and from these classes successfully, something that involved travelling on public transport.

Outcome

By the end of her programme Caroline had achieved almost all of the goals set. She was travelling more independently, was more confident in public situations. Her scores on the CAPS changed significantly over time and are shown in Figure 15.1. At the time of

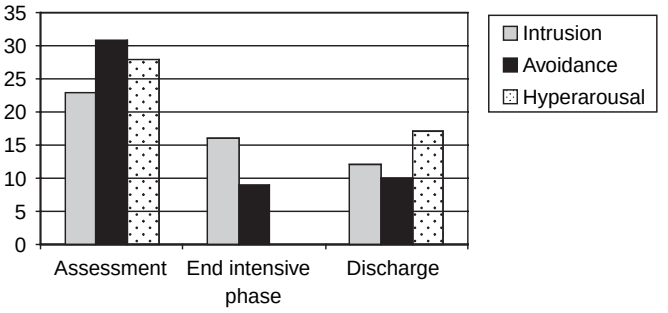

Figure 15.1: Scores for Caroline on the CAPS assessment at the initial assessment, at the mid-point of her rehabilitation programme following the intensive phase and then at the end of the programme (*note that the hyperarousal component was not recorded at the mid-point).

discharge from the programme, Caroline was pursuing her art through attending classes, though had not progressed to having a specific plan for return to paid work. Over a period of time following discharge, however, she was able to return to working as an artist. Following discharge from the rehabilitation programme she returned to her home area and was supported by local services (Psychiatry, Clinical Psychology and Occupational Therapy) to continue to do the work that she had undertaken.

Caroline is not typical of people who have head injuries. However, in her case, although the PTSD was clearly the main disabling factor limiting her ability to carry out normal activities of daily living and preventing her from returning to work, our formulation was that the cognitive difficulties she suffered as a result of the injury were also contributing to her difficulty in overcoming the PTSD. It is of course impossible to be sure of the precise relative contributions of mood and cognitive problems to everyday difficulties and the nature of the interaction between them. However, it seems sensible to try to address both issues simultaneously, which was what happened in this case with one strand of Caroline's programme focusing on management of PTSD symptoms directly and another strand focusing on use of strategies (such as the use of her personal organizer and planning framework and strategies for managing concentration difficulties) which aimed to help her complete everyday functional tasks, compensating for her difficulties in memory, attention and speed of information processing. As Bryant (2001) notes, impaired memory and attention 'may restrict the TBI patient's ability to employ coping strategies that effectively manage posttraumatic stress' (p. 941).

General discussion

Most people with TBI do not suffer such extreme PTSD. As discussed briefly at the beginning of this chapter, there has been some controversy regarding the incidence of PTSD after brain injury. This is in part because of methodological problems associated with the use of some of the more common measures of PTSD symptoms. Sumpter and McMillan (2006) found that, based on self-report on a PTSD symptom questionnaire (Post-traumatic Diagnostic Scale: Foa *et al.*, 1997), 59% of respondents reported symptom levels in the caseness range. However using the CAPS structured interview approach the caseness figure was only 3%. In explaining the discrepancy in the figures, Sumpter and McMillan argued that people sometimes made errors completing the questionnaires, sometimes misattributed the question to other events (and not the accident itself) or

made more concrete interpretations of the questions and related the questions to cognitive impairments arising from the head injury rather than mood-related PTSD symptoms. This highlights how important it is to be very cautious in the use and interpretation of mood questionnaires with people with head injury. This issue has been highlighted in relation to other more general mood questionnaires such as the commonly used Hospital Anxiety and Depression Scale (Snaith and Zigmond, 1994), which has several items on it (e.g. I feel slowed down; I can enjoy a good book or radio or television programme) which may be endorsed as a result of cognitive or motor problems after brain injury rather than as a consequence of mood disorder (see Dawkins *et al.*, 2006). To assess for PTSD, and indeed any other mood disorder, in the context of brain injury, questionnaires can provide a useful starting point, but should always be followed up with clinical interview in order to determine the specific nature of the problems. Structured interviews such as the CAPS provide a useful framework for examining for PTSD, but even here it is important to be sure that the client understands the true nature of the questions asked.

In spite of the fact that questionnaire-based studies may overestimate the prevalence of PTSD after TBI, it is now relatively well accepted that even in the context of loss of consciousness key symptoms associated with PTSD may develop following both mild and severe TBI. It has been suggested that the symptom profile for those who suffer PTSD after TBI might be different than for those who have not suffered TBI (Bryant, 2001). Specifically, TBI patients may experience less intrusive memories and nightmares, but meet the re-experiencing criteria because they experience psychological distress in relation to reminders of the trauma. Clarifying this issue is more than just an issue of convenient diagnostic labels because if there is a different symptom profile, there may be implications for treatment, but further research is required. One possibility is that as a result of the loss of consciousness and post-traumatic amnesia explicit recall of events is less likely, but that some implicit recollection in response to specific triggers is possible. Bryant (2001, p. 943) notes one treatment implication of this is that it may be imperative to conduct exposure treatment through eliciting trauma-related anxiety by exposing the client to salient reminders of the trauma rather than relying on spontaneous recall by the client. Relevant to this point, Williams *et al.* (2003) reported the case of KE, another client who undertook the rehabilitation programme at the Oliver Zangwill Centre. KE suffered a severe TBI in a road traffic accident at night. His girlfriend, a passenger, died in the accident. He was in coma for two days and had a post-traumatic amnesia of about a week. He suffered multiple skull fractures and facial and orthopaedic injuries. He attempted to return to work, but could not cope. He suffered anger outbursts. He had moderate levels of impairment in speed of information processing, memory and attention. KE had an island of memory for the trauma event, remembering being trapped in the car, feeling he was going to die, reaching for his girlfriend and realizing she was dead. It was not possible to determine the veracity of this memory and whether or not it was constructed from information he received after the event. Nevertheless, recollecting this caused him distress. Similarly, specific situations could trigger distress such as driving at night in the rain, he would become overwhelmed with the feeling that the event was happening again and had to stop the car.

KE underwent the rehabilitation programme and, as with Caroline, the programme focused both on management of mood and learning to use strategies that would compensate for memory and attentional difficulties. The programme goals negotiated with KE focused on (1) planning and carrying out specified daily living tasks (childcare and

renovation work) at home, (2) managing his anger, alcohol and PTSD symptoms such that he would reduce the frequency of major arguments (defined in terms of extreme verbal aggression) with his new girlfriend to zero over at least a one-month period and (3) gaining part-time employment.

KE learned to use an electronic organizer (Personal Digital Assistant – PDA) to help him plan and manage his daily activities. He scheduled tasks and used alarms to prompt him to finish tasks and move on to others (e.g. finishing work on a DIY (do-it-yourself) task to do things with his children). Mood management work focused in part on management of alcohol intake (which had become a problem), sleep and anger, and then also on specific work on PTSD symptoms. Exposure work involved sessions in which he was asked to talk about current trauma re-experiences, whilst being prompted to use relaxation strategies. For example on one occasion he had become distressed while watching a television police drama, feeling breathless and agitated. In the session while describing this he also described having problems breathing, feeling pressure in his chest as he had in the accident when trapped by the steering wheel. He also experienced the smell of blood and fumes. He initially became agitated in the session, but with guidance in the use of relaxation techniques he gradually became able to recall this island of memory without the surge of anxiety. Anger management work led to improvement in his relationship with his new girlfriend.

During the course of his programme KE also worked towards returning to employment and following various 'taster' placements, was able to obtain part-time employment in a DIY store.

Conclusions

A significant proportion of people who suffer a brain injury will experience distress in response to reminders or memories of their trauma event. Memories may be islands of memory of experiences during the trauma or may be constructed on the basis of information they have been told. As a result of fear conditioning or other implicit memory processes distress may be experienced in response to trauma-related situations or reminders. For some people, such as Caroline, there may be full recollection of the traumatic event resulting in the common profile of PTSD symptoms.

Because of the overlap between common cognitive consequences of brain injury and symptoms of PTSD it is important to be cautious in the diagnosis of PTSD after brain injury. Symptom questionnaires can be helpful, but PTSD should not be diagnosed on the basis of questionnaire responses alone.

Cognitive impairments may interfere with the ability to manage symptoms and to engage successfully in everyday activities, which would normally contribute to improving PTSD. The cases described in this chapter highlight how a rehabilitation programme that simultaneously addresses both the cognitive and the mood difficulties may be effective in treating PTSD in the context of brain injury.

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Chapter 16

Interdisciplinary vocational rehabilitation addressing pain, fatigue, anxiety and impulsivity: Yusuf and his 'new rules for business and life'

Fergus Gracey, Donna Malley and Jonathan J. Evans

In order to illustrate our developing approach to interdisciplinary rehabilitation, we describe our work with Yusuf. He was one of the first clients with whom teamwork was organized across a range of impairments, activities and contexts, which in turn fed into increased social participation in one key goal area. The work also provides a good example of formulation-based rehabilitation, which provides a means of integrating assessment results, and developing a 'shared understanding' across the team and with the client. Since our work with this client we have sought to develop these principles further to become formalized aspects of the rehabilitation programme, as described in the 'core components' (Chapter 4), and in more detail in our work with Judith (Chapter 17). The case also highlights specific successful interdisciplinary interventions for pain and fatigue delivered as part of the integrated rehabilitation programme.

History of injury

Yusuf was involved in a car accident in May 1998. He was in coma for a week, and post-traumatic amnesia was reported to last for about a month, indicating a very severe head injury. Computerized tomography (CT) scans at the time of injury identified a left fronto-temporo-parietal subdural haematoma, which was causing some mass effect on the left cerebral hemisphere and left lateral ventricle.

Social history

Yusuf was a 35-year-old man (32 at time of injury) who lived with his wife and three young children. At the time of his accident he was managing his own successful import/export trading house. Since his accident he had given up all but one aspect of this business. Yusuf's

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brother noted family concerns as to how the business was doing and said it is very dependent upon 'a few loyal customers and a very tolerant supplier'. Yusuf was also trying to develop some internet-based business ideas.

Detailed assessment

Yusuf was assessed at the Oliver Zangwill Centre for Neuropsychological Rehabilitation in the spring of 2001, almost three years post-injury. Following a one-day preliminary assessment, Yusuf returned for the detailed assessment, carried out over two weeks. The areas covered were the same as those described for Peter in Chapter 13 and will not be repeated here. In brief, assessment included discussion with the client and family members, identifying strengths, weaknesses and potential goals for rehabilitation. The interdisciplinary assessment also covered awareness, mood and behaviour, neuropsychological functioning, physical functioning, communication, and areas of functional difficulty at home, work and in leisure.

Difficulties identified from interview with Yusuf and family

Yusuf reported a long list of problems, especially of a physical and emotional nature. This is reflected in his elevated self-ratings of problems on the European Brain Injury Questionnaire (EBIQ; Teasdale *et al.*, 1997) on which he scored 137 (from a possible maximum of 183, minimum of 61), and corroborated by his wife's ratings on the same measure of 144 and 152 over two occasions prior to the start of rehabilitation. Key self-reported areas of difficulty are presented in Table 16.1. Whilst 'reduced insight' was noted by both Yusuf and family, it appears from the list that intellectual awareness (Crosson *et al.*, 1989) of cognitive problems was relatively low by comparison with awareness of physical, emotional and social changes. Of note was Yusuf's sense of deterioration in his physical state, and perhaps heightened attention to such difficulties. Yusuf's brother particularly commented on his brother's poor decision-making at work, resistance to taking advice and not discussing decisions with others.

Yusuf's wife was interviewed and endorsed many of the areas of difficulty that had been highlighted previously. She noted that one of the most significant changes in her husband is that he always used to leave things until the last minute, but still managed to get things done – this was no longer the case. She also highlighted how he cannot be rushed and has to work at his own pace, and when he forgets things he often becomes highly self-critical and generally low in mood. She reported that he was unable to deal with the children and domestic tasks and was vulnerable to irritability.

Summary of social participation restrictions

This particular mix of impairments, activity restrictions and personal and social contexts (see Figure 16.1, summary of assessment formulation) contributed significantly to the following social participation restrictions:

- Difficulty completing desired work roles effectively
- Reduction in quantity and quality of interpersonal relationships
- Reduction in quantity and quality of activities
- Inconsistent rest periods, fluctuating energy levels
- Reduction in communication abilities and confidence.

Table 16.1: Areas of difficulty identified by Yusuf and family members at initial assessment

	Yusuf	*Family (brother and wife)*
Physical changes	Deaf in right ear Double vision Very weak right-hand side Delayed temperature sensation on the right-hand side Co-ordination problems on the left-hand side Balance problems Dizziness Tire easily Pain all over all the time Difficulty walking and cannot run at all Cannot stand for more than 2–3 minutes Things have deteriorated over time (he had been able to walk for a couple of miles post-injury, but cannot do anything like this now)	Family members endorsed all these problems and added that Yusuf had also gained weight
Emotional and behavioural changes	Agitation, anger and irritability, especially when tired Lack of awareness and insight Emotional lability Self-centredness Depression Anxiety Inflexibility and obsessionality Difficulty handling noisy situations	Family members reported increased irritability and frustration in Yusuf, as well as limited insight, difficulty interacting with others and avoidance of social interactions Self-criticalness and low mood also noted
Cognitive changes	Slow thinking speed Poor short-term memory Impulsivity and disinhibition Poor 'multifunctional' thinking (by which Yusuf meant decision-making and multitasking) Confusion in new surroundings	Family members identified poor concentration, short-term memory problems and difficulty making decisions

Related to this, Yusuf's goals for rehabilitation were as follows:

- To be able to work more easily and efficiently
- To reduce physical symptoms of pain and fatigue
- To improve memory and concentration skills
- To be able to help more at home with the family and local community
- To feel less irritable.

Observation and monitoring during assessment period

Daily monitoring was carried out during the detailed assessment period by both Yusuf and the team. Yusuf highlighted the impact of pain and fatigue during his time at the Centre. This was clearly evident in his use of frequent breaks and taking longer rests after lunch.

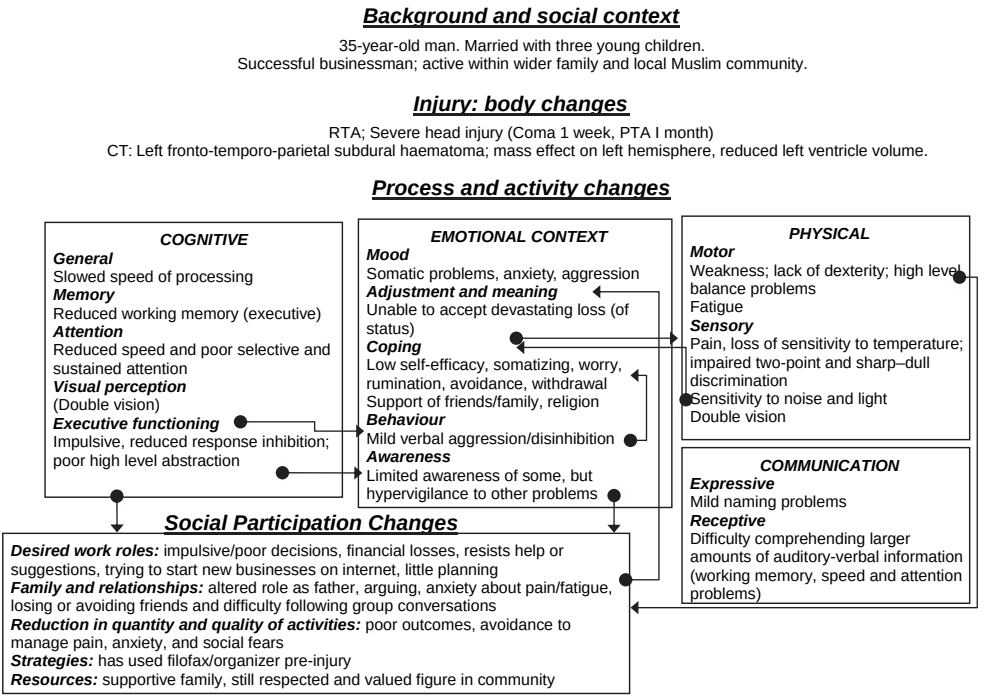
Background and social context
35-year-old man. Married with three young children.
Successful businessman; active within wider family and local Muslim community.
Injury: body changes
RTA; Severe head injury (Coma 1 week, PTA I month)
CT: Left fronto-temporo-parietal subdural haematoma; mass effect on left hemisphere, reduced left ventricle volume.
Process and activity changes
COGNITIVE
General
Slowed speed of processing
Memory
Reduced working memory (executive)
Attention
Reduced speed and poor selective and sustained attention
Visual perception
(Double vision)
Executive functioning
Impulsive, reduced response inhibition; poor high level abstraction
EMOTIONAL CONTEXT
Mood
Somatic problems, anxiety, aggression
Adjustment and meaning
Unable to accept devastating loss (of status)
Coping
Low self-efficacy, somatizing, worry, rumination, avoidance, withdrawal
Support of friends/family, religion
Behaviour
Mild verbal aggression/disinhibition
Awareness
Limited awareness of some, but hypervigilance to other problems
PHYSICAL
Motor
Weakness; lack of dexterity; high level balance problems
Fatigue
Sensory
Pain, loss of sensitivity to temperature; impaired two-point and sharp–dull discrimination
Sensitivity to noise and light
Double vision
COMMUNICATION
Expressive
Mild naming problems
Receptive
Difficulty comprehending larger amounts of auditory-verbal information (working memory, speed and attention problems)
Social Participation Changes
Desired work roles: impulsive/poor decisions, financial losses, resists help or suggestions, trying to start new businesses on internet, little planning
Family and relationships: altered role as father, arguing, anxiety about pain/fatigue, losing or avoiding friends and difficulty following group conversations
Reduction in quantity and quality of activities: poor outcomes, avoidance to manage pain, anxiety, and social fears
Strategies: has used filofax/organizer pre-injury
Resources: supportive family, still respected and valued figure in community

Figure 16.1 Interdisciplinary 'summary of assessment formulation' for Yusuf, broadly based on the World Health Organization International classification of functioning as described in more detail in Chapter 2. RTA, road traffic accident; PTA, post-traumatic amnesia.

Team members often had to interrupt his rest to fetch him for his sessions. Yusuf walked around the Centre slowly and with effort using a stick at all times, and was distracted during assessment sessions by pain.

Neuropsychological assessment

The results identified significant drops in speed of information processing, verbal immediate and delayed memory (perhaps secondary to other influences such as attention, slowed speed of processing and executive difficulties on encoding), verbal working memory and attention (both sustained and divided attention) were identified. Executive difficulties with inhibiting a dominant response, generating new ideas and self-monitoring performance were also identified. No significant difficulties were seen with visuo-spatial skills.

Assessment of mood, emotional adjustment and behaviour

Yusuf engaged well with the assessment process, demonstrating good awareness of his own emotions. On a measure of anxiety and depression (Hospital Anxiety and Depression Scale (HADS); Zigmund and Snaith, 1983) his score for anxiety was elevated into the clinical range, whereas that for depression was not. He reported negative thoughts about himself consistent with low self-esteem although this was not formally measured. On the General Health Questionnaire (28 item version: GHQ-28; Goldberg and Williams, 1988) his ratings of items on the somatic subscale were elevated, as were items on an aggression

questionnaire relating to hostility, anger and verbal aggression, being 1 standard deviation above the norms for a non-brain injured, male sample. He reported incidents of high levels of frustration 1–2 times per day.

Yusuf reported concern about his pain problem as he had received conflicting information regarding possible causes. The McGill Pain Questionnaire (MPQ; Melzack, 1975) was used to assess psychological aspects of pain. The measure involves identifying areas of pain, and choosing from a large list of adjectives those that best describe pain experienced. Yusuf endorsed many of the items and chose items indicating a strongly negative pain experience, and gave high ratings of pain intensity. He reported feeling anxious about prospective situations in which he may not be able to control his pain. Hypervigilance or selective attention to physical symptoms was significant. Assessment of coping behaviour from observation and interview highlighted withdrawal and avoidance as dominant coping strategies, with some ineffective attempts to problem solve and 'rationalize' or reason things out. Yusuf also reported a tendency to ruminate on frustrations and irritations with the effect of increasing negative mood. Reduced executive abilities of flexible thinking and inhibition were suggested to be impacting upon his ability to cope effectively, manage selective attention to 'threats' (physical symptoms and ruminative thoughts) and to inhibit emotional reactions.

Assessment of language and communication

Yusuf was assessed using the Measure of Cognitive Linguistic Ability (MCLA; Ellmo *et al.*, 1995).

Receptive language

Yusuf had difficulties recalling details of verbal information. On reading comprehension tasks, Yusuf performed within normal limits on functional tasks but performance was mildly impaired on passages containing inferential information. The time taken to complete the tasks was markedly slower than would be expected. Yusuf reported that in day-to-day situations he misreads words and needs to go back and check. On tasks of verbal abstract reasoning Yusuf displayed some difficulty in interpreting the abstract meanings in full.

Expressive language

Yusuf reported that Portuguese was his first language although his primary language was Gujurati. He became fluent in English in his early teens and at the time of assessment had lived in the United Kingdom for 20 years. He became deaf in his right ear as a result of the accident. He also reported difficulties with word finding, confirmed on testing with poor performance on a visual confrontation naming task. On written tasks Yusuf produced a well-constructed passage with correct sentence structure and punctuation. However, he noted that his written communication needed checking and he noticed frequent errors even on e-mails he had checked.

Assessment of physical functioning

Yusuf's main physical injuries during his accident included a fractured left collar bone, cuts and bruises and, of course, his brain injury. Yusuf said that he made a good physical recovery following his accident and that he was able to walk easily for an hour or more. He described his difficulties with pain and decreased function. He said that physically things

had started to deteriorate over the past 18 months. Due to his difficulties with balance he started using a walking stick. He also said that at home and at work he is now creating a fairly protective environment to reduce demands that may impact on pain or other aspects of physical functioning.

Vision

Yusuf suffered double vision. He had had an operation to try to improve this but with limited effect, and used glasses with an opaque lens to compensate.

Balance

Yusuf's balance was briefly looked at via a stork stance test. He was only able to stand on his right leg for 6 seconds and on his left for 3 seconds and was very unsteady on either leg. Whilst walking, he lost balance easily and required the stick to save him. He reported that he found walking and balancing much more difficult when he was trying to talk.

Sensation

The Rivermead Somatosensory Assessment Battery (RASP; Winward, Halligan and Wade, 2002) was completed with Yusuf. This showed impaired temperature discrimination, two-point discrimination and sharp and dull discrimination along the whole of his affected (right) side.

Summary of assessment

These assessment results were pooled into a broad framework based on the World Health Organization International Classification of Functioning, Disability and Health (WHO-ICF; World Health Organization, 2001). This links client background (context) and injury (body) to strengths, weaknesses (impairments, processes and activities), emotional adjustment (personal and social contexts) and supports or resources (physical and social contexts), to provide an account or formulation of presenting functional difficulties and barriers to achieving goals (social participation). Here we present this summary in diagram form (Figure 16.1), based on the formulation created by the team following detailed assessment.

In summary, the formulation highlights how specific 'catastrophic' meanings relating to loss of roles and status in home, work and social domains, coupled with a pre-injury ability to multitask and achieve his aims with minimal planning, and post-injury limitations in cognitive and physical abilities, may account for Yusuf's difficulty coping, impulsive decision-making, resistance to use support or implement strategies or advice, and failure to achieve planned tasks. The interplay between poor coping, emotional adjustment and physical functioning secondary to pain and fatigue was seen as underpinning the deterioration in physical functioning.

Rehabilitation programme

Following the 2-week assessment Yusuf returned for a 20-week intensive rehabilitation programme. During the first 10 weeks, Yusuf attended the intensive programme at the Centre 3 days per week, this was followed by a 10-week community integration period, involving less time at the Centre, and more time engaged in community activities (especially in the workplace).

Goal setting

We translated the goals identified by Yusuf into 'SMART' goals in order to allow assessment of goal attainment. These were:

1. Yusuf will implement strategies to complete specified work roles effectively (as rated by himself and his brother).
2. Yusuf will demonstrate use of an identified memory and planning system, to enable him to complete at least 70% of planned activities on a weekly basis without reporting excessive fatigue.
3. Yusuf will demonstrate effective use of strategies to manage stress, anxiety and anger in specified situations within and outside the Centre.
4. Yusuf will demonstrate use of adaptive strategies for managing pain, and will rate himself as more confident in coping with pain in specified situations within and outside the Centre.

As a standard part of the programme clients are supported to develop their own understanding of their injury as described in Chapter 5. A fifth goal was thus also set:

5. Yusuf will report in writing an accurate understanding of the nature and consequences of his brain injury, consistent with his detailed assessment report.

Work towards these goals involved a combination of individual and group sessions providing information about, and ways of addressing, the specific factors underpinning barriers to achieving these goals. In individual sessions Yusuf worked on cognitive rehabilitation for attention and executive problems. Cognitive behaviour therapy (CBT) was provided for Yusuf to tackle low self-esteem, unhelpful patterns of coping and anxiety-provoking appraisals, and to develop skills such as relaxation and 'mindfulness'. Individual rehabilitation sessions were also provided to work on communication skills and physical functioning. Yusuf also attended the following groups: Communication, Memory, Attention and Goal Management, Mood Management, Psychological Support, and Understanding Brain Injury.

In the following section, rather than provide a broad account of everything undertaken with Yusuf, we will focus on work on physical health, coping and impulsivity, in the context of the vocational goal area. The aim is to highlight the role of collaborative formulation, and how specific interventions were integrated towards the achievement of the functional goal relating to work.

Collaborative formulation

At the start of his programme, Yusuf's presenting difficulties with poor physical stamina, anxiety, irritability and pain behaviour were evident and had a significant impact on his programme. Yusuf was often distracted in sessions, wanted to take breaks, or was late back from rests. Given the structured timetable of the programme, this required attention by the team through discussion in a goal planning meeting, as well as with Yusuf. A plan of action was devised that involved working with Yusuf on developing a collaborative formulation of his experience of 'overload', to be carried out by one of the occupational therapists (OTs). An account of factors affecting tolerance of pain and coping was developed in conjunction with the account of mood-related problems, external triggers and physical problems. This was drawn out by the OT with Yusuf through discussion over two sessions, and is presented

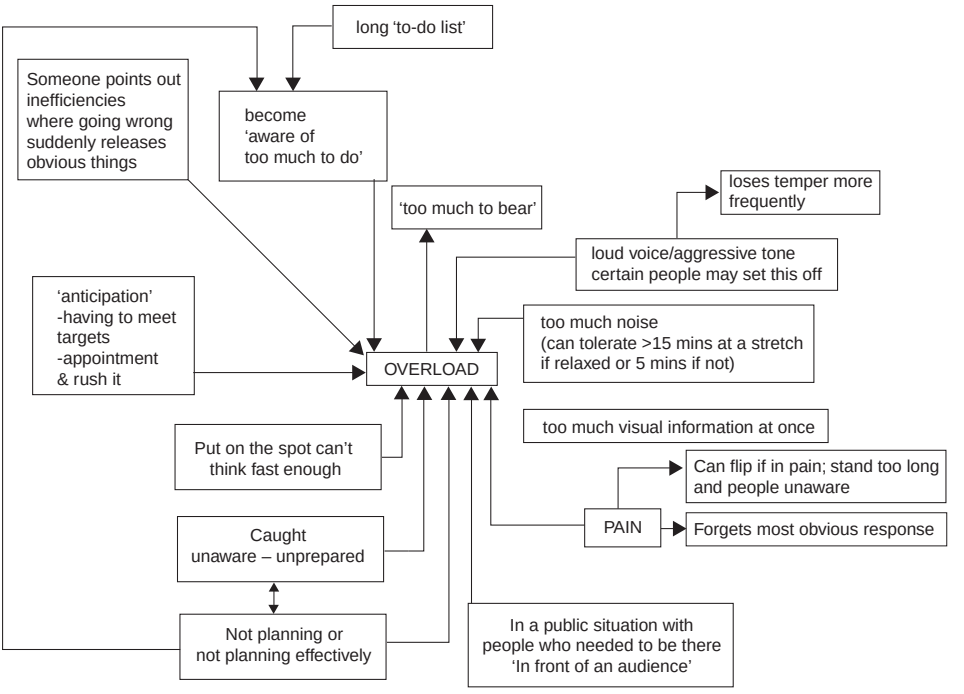
long 'to-do list'
Someone points out inefficiencies where going wrong suddenly releases obvious things
become 'aware of too much to do'
'too much to bear'
loses temper more frequently
loud voice/aggressive tone certain people may set this off
'anticipation' -having to meet targets -appointment & rush it
too much noise (can tolerate >15 mins at a stretch if relaxed or 5 mins if not)
OVERLOAD
too much visual information at once
Put on the spot can't think fast enough
Can flip if in pain; stand too long and people unaware
PAIN
Forgets most obvious response
Caught unaware – unprepared
Not planning or not planning effectively
In a public situation with people who needed to be there 'In front of an audience'

Figure 16.2 Collaborative formulation developed between Yusef and the team early in the rehabilitation process to help understand his experience of 'overload'.

in Figure 16.2. Key factors included stress, fatigue, pain, poor decision-making, impulsivity and environmental factors such as noise and distractions. As suggested in the literature on formulation (Butler, 1998), collaborative development of this formulation helped Yusuf to feel less overwhelmed by the overloaded feeling, and more hopeful about change. The process of formulation was also seen as important to the development of a working alliance with Yusuf.

Managing pain and fatigue

Meanwhile, in sessions with a clinical psychologist Yusuf was introduced to a biopsychosocial model of pain (Gate Control Theory; Melzack and Wall, 1965). Yusuf said he felt this was an acceptable way of understanding his pain. He was then supported to carry out monitoring of rests or 'downtime' over a two-week period to identify the average amount of downtime required per day. This revealed inconsistent amounts of downtime, between 30 minutes and 2 hours per day, taken at different times. He also completed diary monitoring, structured to elicit triggers, appraisals, feelings, behaviour and outcomes. From the monitoring and discussions in individual sessions, it became apparent that whilst Yusuf took breaks on occasions when he felt fatigued or in pain, he also took rests when anticipating a potential increase in pain. This demonstrated that Yusuf was not using consistent strategies for managing stress, pain or fatigue. At times he would spend his rest period worrying about the tasks ahead, which added to the feelings of fatigue and stress. On occasion, Yusuf would fall asleep. Although this sometimes helped improve mood, fatigue

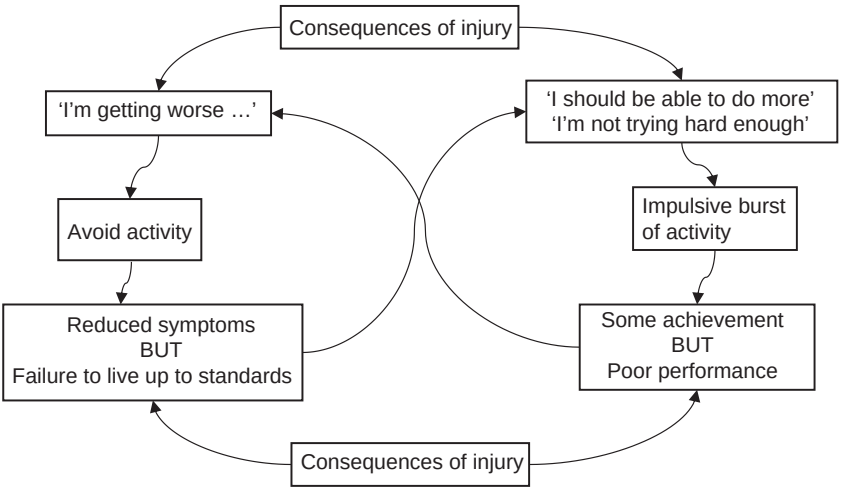

Figure 16.3 Formulation of Yusuf's fatigue based on an adaptation of the cognitive-behavioural model of Surawy *et al.* (1995).

and pain tolerance, at other times it did not have this effect. His pattern of hypervigilance to pain and fatigue, emotionally driven thoughts about the meaning of physical sensations, and high expectations of performance in the context of self-criticism for failure was seen as similar to a cognitive model of chronic fatigue syndrome (Surawy *et al.*, 1995). This has been described as a 'boom–bust' model, and an adapted version was developed and drawn upon for our work with Yusuf (see Figure 16.3).

Following this rationale, intervention involved breaking the boom–bust cycle by rationing rest breaks into a fixed pattern, to help break associations between fatigue-related cognitions and behaviour, and then challenging or responding differently to cognitions. The amount of downtime monitored over the 2 weeks was totalled and the average calculated at about 50 minutes per day. A set pattern of rest breaks totalling 50 minutes per day was thus established: 5 minutes mid morning, 15 minutes after lunch, and 30 minutes in the early evening. Specific times for these breaks were identified for the Centre, at work and at home. This work was integrated with the OTs supporting Yusuf to develop effective systems for managing day-to-day tasks under his memory and planning goal. Yusuf had developed his use of a Psion electronic organizer as part of his memory and planning goal which he was able to use to prompt taking rest breaks. Furthermore, Yusuf had been attending physiotherapy sessions that provided him with the advice to not sit for periods longer than 30 minutes without getting up to stretch, thus this strategy was integrated into the programme.

In order to make more effective use of these rest times, Yusuf received support in practising relaxation and 'mindfulness' meditation. A standard controlled breathing technique was used for relaxation, and a guided mindfulness meditation tape used to practise mindfulness (Kabat-Zinn, 1994). Yusuf was supported to use mindfulness to step back from and accept his experience of, and emotional thoughts about, pain and fatigue. Using mindfulness techniques during his break times, and relaxation during the longer evening rest break, a decrease in amount of 'downtime' was recorded over a two-week period, and Yusuf reported feeling increased control over symptoms, and less anxiety. At this stage of

the programme, the positive self-report and observation of progress in managing pain and fatigue was not corroborated on standardized measures. He reported increased tolerance of pain, and functionally at the Centre his previously fluctuating patterns of rest and disrupted attendance of sessions were significantly improved.

Goal management, memory and planning, and reducing impulsivity

Yusuf's unhelpful and ineffective patterns of activity, seen in part as emotional responses to failed attempts to achieve tasks, were also addressed through development of effective systems for completing day-to-day tasks (both routine and non-routine), and rehabilitation of poor decision-making and impulsivity. In addition to individual and group sessions facilitating understanding of these areas (see Chapter 6 this volume; Evans, 2003; Levine *et al*., 2000), Yusuf completed monitoring sheets to note examples of memory slips. The monitoring of memory slips allowed Yusuf to develop awareness of the range and nature of everyday memory and planning problems, again facilitating engagement in use of compensatory strategies and highlighting specific targets. He was helped to learn specific functions in turn on his electronic organizer, starting with the 'Agenda' function for all scheduled planned activities.

The next plan of action required learning to use the To-Do List function for noting tasks that required scheduling. This enabled Yusuf to achieve the goal of successfully completing 50% of planned activities at home and in his social and community life by the end of the initial intensive phase of the programme. This system was adapted for use in the workplace with support from the OT carrying out vocational rehabilitation. Yusuf developed a daily work routine that started with planning his day using Microsoft Outlook on his PC, and 'isyncing' his Psion organizer with Outlook. He had timetabled rest breaks, and allocated slots for specific work-related tasks, with a slot at the end of the day for dealing with any additional non-planned tasks or queries that arose during the day. Specific workplace-related checklists for effectively managing routine tasks were summarized into tables for Yusuf to apply (see Table 16.2).

Individual work on executive functioning was built on a 'stop–think' strategy to reduce impulsivity. Yusuf was introduced to the rationale for using such a strategy, and practised goal management in relation to set problems in sessions at the Centre, building on exercises carried out in the Attention and Goal Management Group. Despite support, Yusuf did not, at first, generalize this strategy use to other situations, and continued to respond impulsively. Analysis of situations when this happened, and reflection on the collaborative formulation, helped clarify the contribution of factors such as stress, frustration or anxiety levels, environmental factors and cognitive appraisals. This cognitive rehabilitation work was thus integrated into the work on emotional coping. Further exploration of cognitions associated with emotional adjustment highlighted negative automatic thoughts relating to fear of failure fuelling a more impulsive response. On further guided discovery in CBT sessions, Yusuf identified the underlying assumptions associated with these automatic thoughts. These concerned an underlying sense of loss of status in the eyes of others that crossed social, family and work situations. Focusing on work situations, unhelpful but understandable rules for preserving pre-injury identity were identified. These are summarized below:

'Things aren't going well so I should:

- "strike while the iron is hot"
- "act now before I forget"

Table 16.2. Summary of work-related strategies

Tasks involved yarn business	Strategies identified
ORDERING STOCK	
• Check current stock status	• Ask employee to supply weekly stock figures and review on a weekly basis – put on employee's to-do list
• Check or make a sales projection	• Every 2 weeks or once a month (depending on season) check stock currently available and sales projection to decide if need to place an order – reminder on Psion
• Check current status with suppliers	• Check current status with supplier on a weekly basis – reminder on Psion
• Make the order to cover sales projection	• Double check orders before they are faxed
• Receive the order confirmation	• Contact supplier about order after one day – reminder on Psion
• Get the documents from the bank and sign to guarantee payment	• Contact supplier to check order has been shipped after 4 weeks – reminder on Psion
• Receive the goods	• Chase bank after 6 weeks if no documents have been received – reminder on Psion
• Pay	• Check employee has received bank documents, filed them, entered into database, delivered to warehouse and date stock arrived – reminders into Psion when need to check
• Monitor sales in comparison to projection	• Have a set time each week to check above – part of daily/weekly plan
	• Organize working day – complete daily plan and daily review
	• Complete yarn-related work in mornings and web-related work in afternoons
	• Plan when to complete weekly, monthly, quarterly and annual tasks
SALES FLOWCHART	
• Receive an order	• Check employee has completed the order form
• Complete order form	• Don't haggle on price – say you will get back to them
• Fax order form to warehouse	• Consider a prompts pad to note all order related information when answering telephone calls
• Await delivery note	• Immediately complete order form and fax or put on employee's to-do list
• Make up and send out invoice to customer	• Liaise with factoring company on a regular basis – reminder on Psion
• Complete form and send to factoring company	• Organize working day – complete daily plan and daily review
• Await payment from factoring company	• Complete yarn-related work in mornings and web-related work in afternoons with hour at end of each day for urgent to do's

Table 16.2. (cont.)

Tasks involved yarn business	Strategies identified
	• Plan when to complete weekly, monthly, quarterly and annual tasks
Tasks and situations triggering	
• Looking at to-do list and planning at the start of the day	• Notice 'negative predictions' about own ability, time available etc. triggered by looking at morning's plans
	• Take control of attention, use mindfulness to direct your attention back to the task at hand, and away from the negative predictions
	• Complete your plans for the morning
	• Tell yourself 'once I start these tasks I will feel better'
	• DO NOT REST unless it is a set rest time – STICK TO REST TIMES
• 'Surprise demands'	• Stay in the situation
	• Recite a 'zikr' two or three times to distance yourself from negative thoughts and keep your attention in the present
	• 'Stop and think'
	• Ask the person to repeat or clarify if you have not fully taken in what they have said
	• Be assertive with your response
	• If necessary schedule any additional tasks arising during the day for the time for this at the end of the day
	• Demonstrate status by saying 'I'm tied up right now, but can get back to you after 3.00 p.m.

- "make a quick, confident decision so I'm seen as a good businessman"
- "make a quick decision so I will not be challenged"

These rules were seen as understandable attempts by Yusuf to protect himself from threats to his pre-injury identity (an effective manager of profitable businesses, well respected in his community). They were seen as a set of automatic, emotionally 'hot goals' triggered in specific situations that 'trump' any attempts to stick to an intentional goal. Yusuf considered the pros and cons of these rules and 'hot goals' for achieving his goals and began to see how these ways of responding, whilst aiming to cover up problems (to preserve status), in the longer term resulted in poor outcomes and ultimately loss of status. The original collaborative formulation was thus developed further with Yusuf to map out the process of how triggers (threats to identity) were appraised in such a way as to contribute to increased stress and unhelpful coping behaviours (see Figure 16.4).

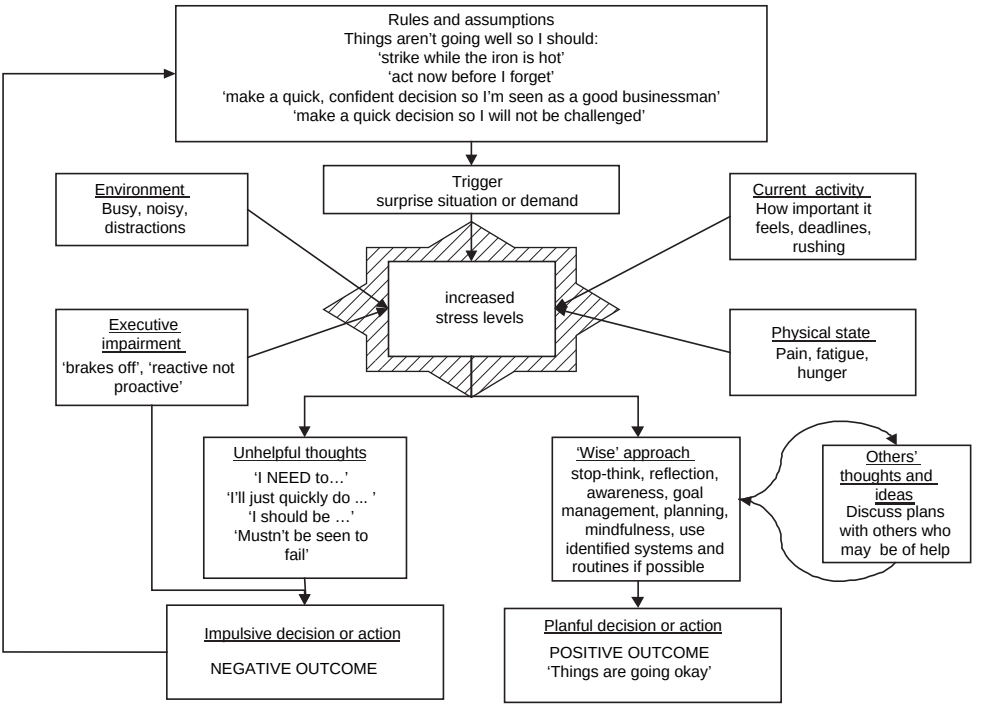
Rules and assumptions
Things aren't going well so I should:
'strike while the iron is hot'
'act now before I forget'
'make a quick, confident decision so I'm seen as a good businessman'
'make a quick decision so I will not be challenged'
Trigger
surprise situation or demand
Environment
Busy, noisy, distractions
Current activity
How important it feels, deadlines, rushing
increased stress levels
Executive impairment
'brakes off', 'reactive not proactive'
Physical state
Pain, fatigue, hunger
Unhelpful thoughts
'I NEED to…'
'I'll just quickly do ... '
'I should be …'
'Mustn't be seen to fail'
'Wise' approach
stop-think, reflection, awareness, goal management, planning, mindfulness, use identified systems and routines if possible
Others' thoughts and ideas
Discuss plans with others who may be of help
Impulsive decision or action
NEGATIVE OUTCOME
Planful decision or action
POSITIVE OUTCOME
'Things are going okay'

Figure 16.4 Formulation linking cognitive, emotional and physical factors underpinning Yusuf's unhelpful patterns of responding, and highlighting cognitive and behavioural strategies that may offer a more adaptive way of responding.

Additional factors such as pain, fatigue, hunger and environmental noise and distractions were also added as further factors contributing to stress. It was suggested that these factors might increase the likelihood of an impulsive response. So in addition to routines and structures developed with the OTs for reducing opportunities for impulsivity, and increasing successes, the cognitive-behavioural formulation allowed integration of additional strategies for challenging old rules and assumptions, and developing new rules and assumptions based on strategy use and positive outcomes. These strategies included daily relaxation to manage general stress levels, and use of goal management for problem solving, decision-making, and staying on track with tasks. Yusuf also developed a portable 'mindfulness' approach to noticing and stepping back from unhelpful thoughts in the moment, based on the Muslim practice of repeating a private prayer or 'zikr'. Intermittent alerts on the Psion organizer synchronized with Outlook on his PC were used initially to support self-monitoring and application of these strategies in the workplace.

Outcomes

Goal attainment

1. Yusuf will implement strategies to complete specified work roles effectively (as rated by himself and his brother).

Yusuf achieved this goal applying the combined memory and planning, goal management, mindfulness, pacing and fatigue management strategies. He initiated the idea of altering his daily routine further such that, rather than attempting unsuccessfully to expand his work into new ventures, he made his 'second business' making the first business (importing and wholesaling) more efficient. It was evident that he had successfully challenged his underlying assumptions about how to be seen as a 'good' businessman, and reported his new 'rules for business and life' (see Appendix 16.1).

2. Yusuf will demonstrate use of an identified memory and planning system, to enable him to complete at least 70% of planned activities on a weekly basis without reporting excessive fatigue.

Yusuf achieved this goal, completing identified tasks in work, family and community activities.

3. Yusuf will demonstrate effective use of strategies to manage stress, anxiety and anger in specified situations within and outside the Centre.

Yusuf reported improvement in these areas by the end of the programme, especially in the work place. Family reported some improvement in this area at home. Consistent with this, standardized measures revealed a mixed picture on ratings made by himself and his wife (see Figures 16.7 to 16.9).

4. Yusuf will demonstrate use of adaptive strategies for managing pain, and will rate himself as more confident in coping with pain in specified situations within and outside the Centre.

This goal was clearly achieved with a reversal in the physical deterioration evident at initial assessment and at the start of his programme. Yusuf stopped using his stick, made much more effective use of his rest times, and had significantly reduced his unhelpful use of rest time which led to the 'boom' and 'bust' situation. His reports of, and concern about, fatigue also diminished, although pacing and other fatigue management techniques continued to be required.

5. Yusuf will report in writing an accurate understanding of the nature and consequences of his brain injury, consistent with his detailed assessment report.

A written portfolio was prepared by Yusuf detailing the nature and consequences of his injury. He reported feeling more confident in sharing his understanding of his injury with others. More importantly, Yusuf's initial intellectual awareness had moved towards the anticipatory awareness level, as demonstrated by his initiation of strategy use in his day-to-day life.

Questionnaire measures

Self-ratings and ratings by Yusuf's wife on the EBIQ (Teasdale *et al.*, 1997) indicated broad improvement in all domains over the course of the programme, with some fluctuations after the end of the programme (see Figure 16.5). Somatic, communication and cognitive areas demonstrated clear and consistent improvement on both self and other ratings. A similar pattern was noted on the Dysexecutive Questionnaire (DEX, from the Behavioural Assessment of the Dysexecutive Syndrome, BADS; Wilson *et al.* (1996); see Figure 16.6), with improvement over the programme and slight deterioration at follow-up, but not returning to pre-rehabilitation levels.

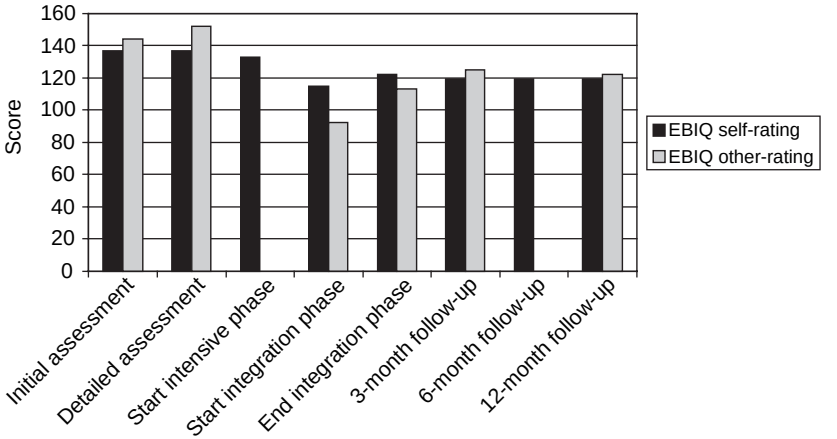

Figure 16.5 European Brain Injury Questionnaire 'total' scores for Yusuf (as rated by himself (dark grey) and his wife (light grey)) for the programme and one-year review period.

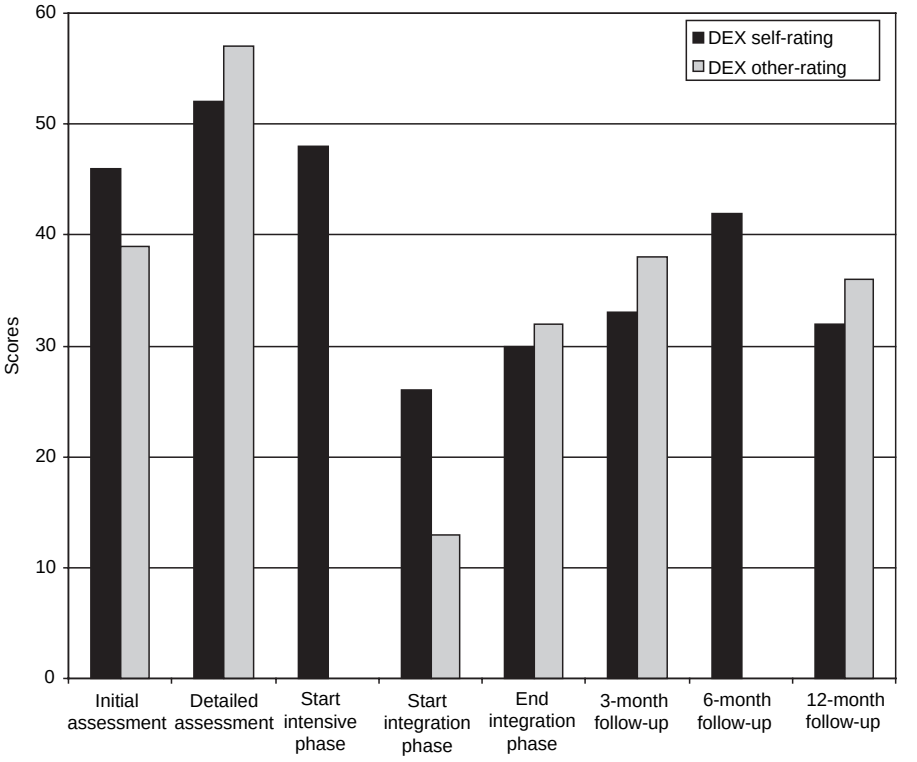

Figure 16.6 Dysexecutive questionnaire scores for Yusuf (as rated by himself (dark grey) and his wife (light grey)) for the programme and one-year review period.

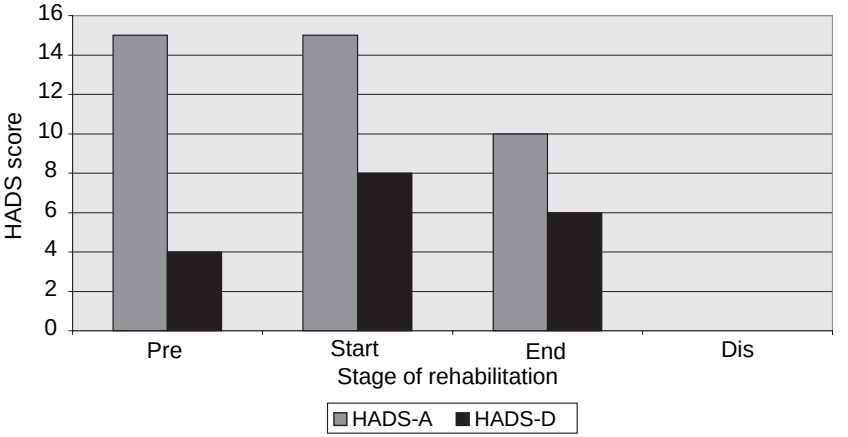

Figure 16.7 Changes in Yusuf's anxiety and depression over the programme as measured by the Hospital Anxiety and Depression Scale. HADS-A = anxiety subscale, HADS-D = depression subscale; Pre = detailed assessment; Start = start of intensive phase; End = end of integration phase; Dis = discharge at end of 12-month follow-up period; note, measures were not taken at discharge.

Measures of emotional adjustment showed more varied outcomes. On the HADS, initial anxiety levels had dropped by the end of the programme (Figure 16.7). The depression score on this measure increased through the programme, perhaps consistent with increased awareness and adjustment to this, decreasing at the end of the programme but not to the initial level. Positive change as measured on the GHQ-28 (Goldberg and Williams, 1988) was clearer (Figure 16.8), especially with regard to reduction of somatic symptoms, consistent with our observations, reports and the EBIQ subscale. These measures thus support at least partial emotional adjustment, and effective reduction or management of somatic symptoms associated with stress, fatigue and pain. Aggression questionnaire subscale measures (Figure 16.9) highlight a reduction in physical and verbal aggression, and anger, but little change in self-rating of feelings of hostility.

'Rules for business and life'

At the first follow-up meeting, Yusuf presented a list of new 'rules for business and life' (see Appendix 16.1). These were compiled from sayings and reflections consistent with aspects of his religious belief and values, carrying meanings associated with adaptive post-injury adjustment, as well as conveying messages helpful for maintaining strategy use.

In summary, this work highlights how development of a shared understanding between the client and team (in this case of what Yusuf described as 'overload') led to development of a more elaborated formulation allowing identification of strategies. Models of pain behaviour, chronic fatigue and executive function integrated into a cognitive-behavioural therapeutic framework were especially influential for organizing interdisciplinary working. The recognition of psychological aspects of pain and fatigue, and experiments to develop less anxious appraisals and more adaptive coping (including physiotherapy and OT input) for these difficult post-injury symptoms helped establish a sense of hope and engagement in rehabilitation. More importantly perhaps was the need to engage the client in changing patterns of behaviour that were designed to maintain pre-injury identity, including feelings of status and respect within his family and wider community. Here the role of speech and

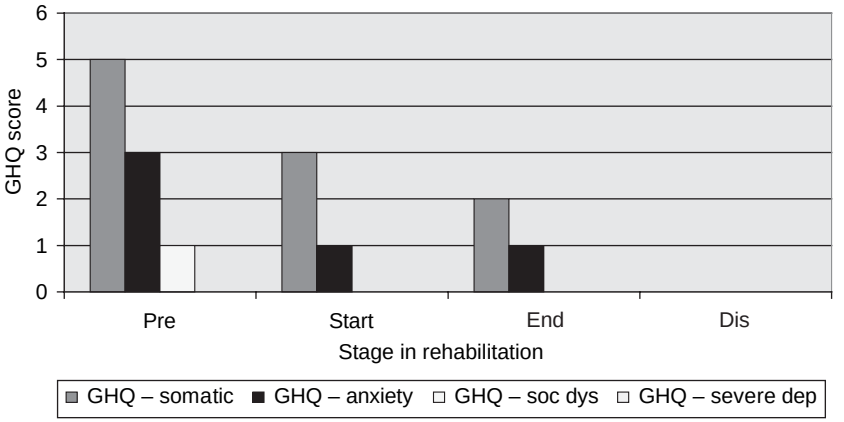

Figure 16.8 Changes in Yusuf's psychosocial functioning over the programme as measured by the 28-item General Health Questionnaire (GHQ-28). soc dys = social dysfunction subscale; severe dep = severe depression subscale; Pre = detailed assessment; Start = start of intensive phase; End = end of integration phase; Dis = discharge at end of 12-month follow-up period; note, measures were not taken at discharge.

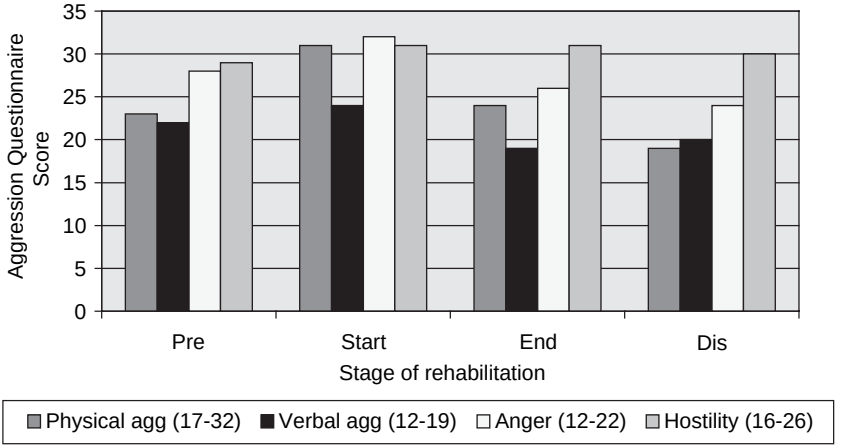

Figure 16.9 Changes in Yusuf's aggression on the four 'aggression questionnaire' subscales (numbers in brackets show the average range for healthy male respondents for each subscale). Pre = detailed assessment; Start = start of intensive phase; End = end of integration phase; Dis = discharge at end of 12-month follow-up period; note, measures were not taken at discharge.

language therapy in supporting effective communication in home, social and work settings was especially pertinent. The psychological challenge of letting go of established behaviour that provides safety in the short term in order to allow potential for more adaptive change is significant, and is also explored in our work with Judith (Chapter 17). The integration of context-specific and general compensatory systems developed in occupational therapy, and communication strategies and skills, was integral to the work on psychological change. The rehabilitation programme and latterly the workplace provided contexts in which behavioural experiments could be carried out to challenge unhelpful appraisals and develop more flexible, adaptive and positive rules, assumptions and strategies. For Yusuf, his family and

community were able to support him through this process of change, in addition to his rehabilitation. Furthermore he was able to draw on his existing beliefs and values to support the changes that were important to his successful rehabilitation. Such resources and values, however, are not always in place following brain injury, and for some the 'risk' of change in relation to threatened identity is too high, or complexities in the broader system may present a greater challenge to change.

Appendix 16.1: Yusuf's 'rules for business and life'

1. Planning

Plan thoroughly and have a clear strategy in mind at all times. A Daily Diary and a 'To-do' List is a Must.

2. Pace Your Self

Don't Rush – Stop – Think . . . then Act – Use Mindfulness – Control the environment (noise, seating etc.).

3. Information is power

Understand your product – talk to customers and competitors – Go out on the Road – Have a hands on approach. If delegating – try to do it yourself sometimes and see for yourself.

4. Control

Don't loose track of Money matters – Review Figures and Reports Regularly Use PQRST.

5. Be Proactive rather than Reactive

Don't Bottle too much In – Be tactful and Honest but get it out of your system ASAP.

6. Don't shirk from the fight

There are many pitfalls and obstacles on the way – Be determined – once decided Have the will power to go all the way.

7. Focus

Keep focused at all times – Stick to your Plans.

8. No man is an Island

Exchange ideas – Keep in touch with others – Build an informal network – Seek advice (whilst ensuring confidentiality and discretion at all times).

9. Take your Time – Sleep Over Major Decisions

Ask 'w' and 'h' questions. Strengths Weaknesses Opportunities Threats analysis + Look Into Time/Money Factor before deciding – Use Goal Management Framework. Never Volunteer Negative Information.

10. Last but not Least

Walk Away from Potentially Volatile situations.
Learn to Say No.
Learn to say enough for the day.
Try your Best and Put your Trust in the Almighty.

Three rules for everyday situations

- Laziness is from Satan and Haste is From Satan (From Prophet Muhammad)
- Under Promise and Over Deliver, also Under Expect, you will never be let down
- In Adversity: A Wise Man does in a Moment what a Foolish Man Does after a Month (i.e. he resorts to patience and Accepts Reality)

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Chapter 17

Judith: learning to do things 'at the drop of a hat': behavioural experiments to explore and change the 'meaning' in meaningful functional activity

Fergus Gracey, Susan Brentnall and Rachel Megoran

Introduction

The emotional sequelae of acquired brain injury (ABI) are now well documented and increased attention in the literature is being paid to intervention. In addition to this, research has identified the profound impact of ABI on sense of identity (Tyerman and Humphrey, 1984; Nochi, 1998; Cantor *et al*., 2005; Dewar and Gracey, 2007). Ylvisaker and Feeney (2000) present a rehabilitative approach that explicitly involves developing 'identity maps' with their clients, and McGrath and King (2004) describe how behavioural experiments in cognitive behaviour therapy (CBT) can address beliefs and assumptions about self and abilities following ABI. As we described in earlier chapters (e.g. Chapter 4), such work is a key feature of the Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation.

At the OZC we have been developing the application of CBT beyond treatment of Axis 1 emotional disorders following ABI (see Williams and Evans, 2003) to explore applications for facilitating acceptance and adjustment across the holistic rehabilitation process. This case illustrates two important aspects of this innovative modification of CBT: the use of behavioural experiments in rehabilitation (McGrath and King, 2004), and the constructive development of what we call a 'positive formulation' to support identity change and adjustment (Mooney and Padesky, 2000; Ylvisaker and Feeney, 2000). The chapter shows how these methods enabled Judith to change the meanings associated with attempts to engage in meaningful activities through the programme, with some enduring behaviour change maintained for a year post-programme.

History of injury

Judith was a 31-year-old woman who was involved in a road traffic accident one and a half years prior to the start of rehabilitation. Before the accident she worked for a chain

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of retailers as a manager responsible for 'turning round' financially failing stores. The accident occurred when the small van she was driving was struck by another vehicle that landed on the roof of the van. She had no recollection of the accident, a pre-traumatic amnesia of around two hours, and a post-traumatic amnesia of about three weeks indicative of a severe head injury. She sustained a left frontal subdural haematoma, and orthopaedic injuries. She was physically able, but since the accident had not worked and was in receipt of welfare benefits, her social life was restricted and she had lost friends. She continued to live with Pete, her supportive partner of four years, although they had become less intimate in their relationship since the accident.

Social history

Judith was living with Pete in a flat above a shop. During the day she stayed inside the flat except to go downstairs to the shop to purchase a newspaper. She was unable to drive due to seizures. Judith reported that she did not have a social life, and that she lost a lot of friends as a result of the accident. Her family lived at the other end of the country, and relationships with her separated mother and father were strained. Judith and Pete shared a love for motorbikes.

Detailed assessment

Judith's self-reported difficulties and goals

Judith was able to reflect on her strengths and weaknesses showing clear evidence of awareness of her impairments. A range of goals were initially identified by Judith as follows:

- How to deal with finances
- If it is possible to study aromatherapy (this goal was more about aspiration and related to her holding a positive attitude toward the future, rather than a fully worked through vocational plan)
- Be able to manage my mood so I could handle starting a family
- To be able to drive again
- Manage difficulties with problem solving, decision-making, memory, communication, reading, confidence and social life.

Regarding emotional adjustment Judith made the following comments:

- 'I want to not have to wear a mask or pretend to be something I am not'
- 'to stop criticizing myself to the extent I do as this is not helping with confidence'
- 'to be able to control the phobias I have about being outside alone'
- 'I'm in a constant battle with myself'.

Neuropsychological assessment

Standardized neuropsychological assessment of memory indicated impairments of visual and verbal recall immediately and after a delay. Executive functioning tests showed difficulty with manipulation of information in working memory, executive control of attention (switching, dividing, sustaining), and difficulty with response

inhibition. Planning skills were unimpaired, although problems arose with implementation of plans. Performance on tests of emotion recognition and emotion-based decision-making were unimpaired. Functionally, these deficits led to difficulties completing day-to-day tasks without getting distracted (e.g. leaving the bath running, leaving the cooker on), difficulty encoding and retaining information, and difficulty maintaining attention (e.g. being unable to follow TV programmes or films). Memory problems were formulated as stemming from reduced encoding secondary to attention deficits.

Assessment of language and communication

Assessment highlighted communication difficulties secondary to her cognitive deficits, including:

- reduced comprehension for abstract or inferential meaning, and a tendency to be concrete
- disinhibition resulting in increased swearing and poor topic maintenance in social communication
- cognitive and emotional difficulties (anxiety) impacting variably and mildly on word finding
- impulsivity, anxiety and attentional difficulties resulting in a hurried approach to reading and increased occurrence of errors.

Assessment of awareness, emotional adjustment and behaviour

Judith scored in the 'severe' range for anxiety on the Hospital Anxiety and Depression Scale (HADS; Zigmund and Snaith, 1983) and Beck Anxiety Inventory (BAI; Beck and Steer, 1990). Whilst in the 'moderate' range for depression on the HADS, she fell into the severe range on the Beck Depression Inventory (BDI-II; Beck *et al.*, 1996) due to scores on items relating to consequences of traumatic brain injury (TBI) independent of mood (e.g. poor concentration, fatigue, disturbed sleep). Her scores on the Culture Free Self-Esteem Inventory 2 (CFSEI-2; Battle, 1992) indicated low general, social and personal self-esteem. The Social Cognitions (SCQ; Wells, Stopa and Clark, unpublished) and Agoraphobic Cognitions Questionnaires (ACQ; Chambless *et al.*, 1984) identified high levels of belief in specific anxiety-related predictions.

Anxiety or panic triggered in social and other situations, and associated avoidance, including not going out alone, were the main presenting emotional difficulties. Symptoms of depression, obsessive-compulsive checking and rigidity, low self-esteem, irritability and verbal aggression, and hypervigilance and hyperarousal symptoms were present. Although Judith had no recollection of the accident itself, she appeared to have specific instances of heightened anxiety in trigger situations characterized by loud or high-pitched noise and enclosed spaces, which may have been trauma related. These symptoms did not meet Diagnostic and Statistical Manual 4th edition, Text Revision (DSM-IV TR, American Psychiatric Association, 2000) criteria for any specific DSM Axis 1 disorder' but would be coded as Anxiety Disorder Not Otherwise Specified (code 300.00) due to a medical condition not elsewhere classified. Nevertheless, her emotional difficulties were significant, distressing and together with her cognitive difficulties exerted a huge limiting influence on her social participation.

Summary of assessment and initial formulation

As described previously, assessment information was integrated to provide a broad formulation of the functional or social participation restrictions in terms of underlying patterns of strengths and deficits, in the context of pre-injury functioning and lifestyle and social factors. A visual summary of this is not presented, although the key factors are presented below:

Body/process limitations (impairments)

- memory (encoding)
- attention (executive aspects)
- executive function (response inhibition and goal maintenance).

Social participation restrictions (disabilities/handicaps)

- loss of vocational activity
- loss of social and leisure activity
- altered relationships.

Contextual factors

- high levels of anxiety, low mood and self-esteem
- reduced social support networks.

Particular resources for Judith included her continued supportive relationship with Pete, self-awareness and ability to reflect on her self and her situation, and determination to change her situation for the better.

An initial formulation based on the underpinning influence of psychological factors was developed early in rehabilitation (see Figure 17.1). This was based on cognitive models of post-traumatic stress disorder (PTSD) (Ehlers and Clark, 2000) and social anxiety (Clark and Wells, 1995). These models were selected due to the central relevance of cognitions relating to 'threat to self' and 'self as negative social object', which seemed best placed to describe Judith's underlying vulnerability in relation to her emotional difficulties post-injury.

The central theme of ongoing threat to identity, in conjunction with rules for maintaining 'safety', was formulated as underpinning a wide range of behaviours aimed at establishing and maintaining safety (Salkovskis, 1996), each of which have a role in preventing disconfirmation of beliefs, or generating further symptoms which may act as triggers.

Triggers bearing a meaning of (potential) threat to identity (social situations, potential failure or problems being evident to others) resulted in overwhelming physical symptoms of autonomic arousal. Appraisal of these as signs of imminent loss of control, and selective attention to self, symptom or threat led to rapid exacerbation of anxiety, completing an escalating cycle of sense of threat. In the context of increased arousal levels her impairment of executive functioning gave rise to a potential increase in disinhibited behaviour, further appraised by Judith after the event as unacceptable to herself and others. Following escape, and compounded by reduced and selective recall for negative events, guilty rumination and 'black and white' self-criticism arose. Her appraisal of, and attempts to manage, such feelings were thought to prevent disconfirmation of threat appraisals through avoidance-based safety behaviours. Her rumination and attempts at mental control may have been a factor in preventing emotional adjustment and maintaining intrusive doubts (e.g. Ehlers and Clark, 2000).

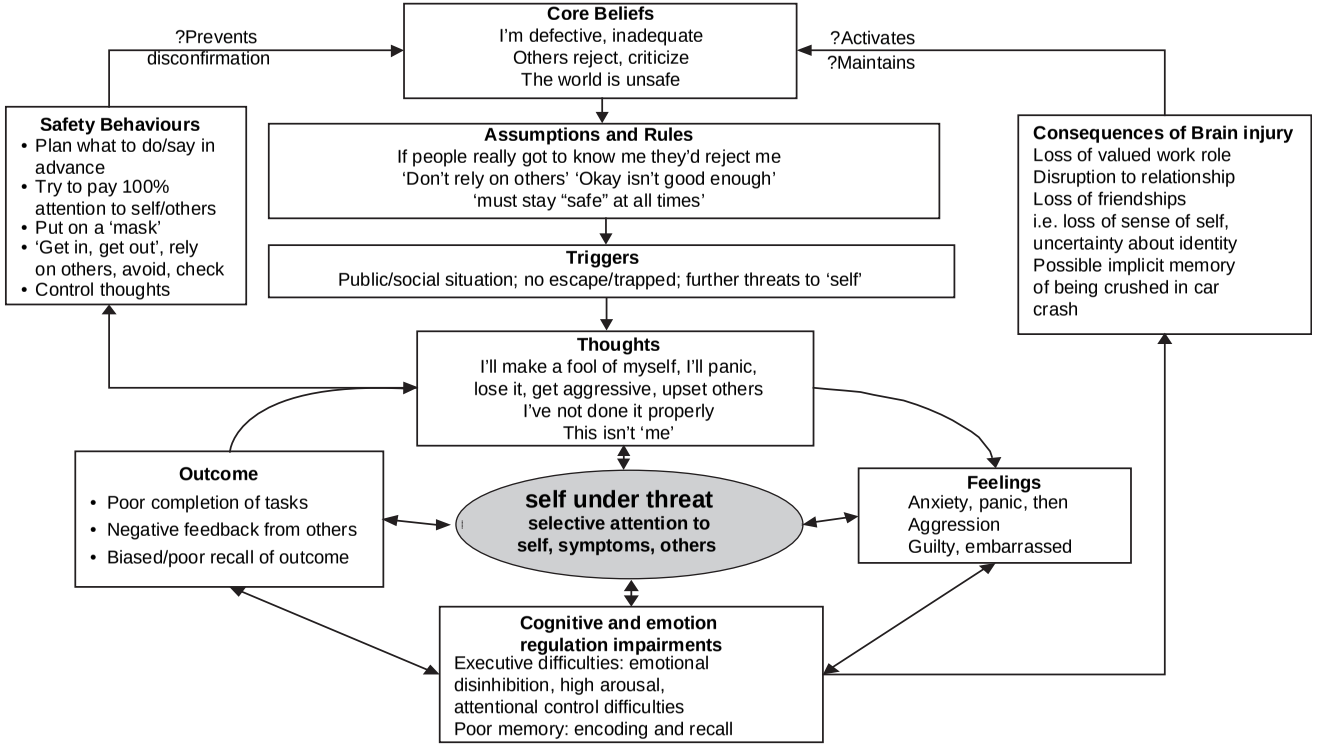
Core Beliefs
I'm defective, inadequate
Others reject, criticize
The world is unsafe
?Prevents disconfirmation
?Activates ?Maintains
Safety Behaviours
• Plan what to do/say in advance
• Try to pay 100% attention to self/others
• Put on a 'mask'
• 'Get in, get out', rely on others, avoid, check
• Control thoughts
Assumptions and Rules
If people really got to know me they'd reject me
'Don't rely on others' 'Okay isn't good enough'
'must stay "safe" at all times'
Consequences of Brain injury
Loss of valued work role
Disruption to relationship
Loss of friendships
i.e. loss of sense of self, uncertainty about identity
Possible implicit memory of being crushed in car crash
Triggers
Public/social situation; no escape/trapped; further threats to 'self'
Thoughts
I'll make a fool of myself, I'll panic, lose it, get aggressive, upset others
I've not done it properly
This isn't 'me'
Outcome
• Poor completion of tasks
• Negative feedback from others
• Biased/poor recall of outcome
self under threat
selective attention to self, symptoms, others
Feelings
Anxiety, panic, then Aggression
Guilty, embarrassed
Cognitive and emotion regulation impairments
Executive difficulties: emotional disinhibition, high arousal, attentional control difficulties
Poor memory: encoding and recall

Figure 17.1 Formulation of social anxiety and panic related to sense of threat to identity, based on Clark and Wells (1995) and Ehlers and Clark (2000). With permission from Elsevier.

Rehabilitation programme

The programme

Judith attended the six-month programme as described in other chapters. During the course of the early stages in rehab, Judith's initial goals were reviewed to identify specific functional rehabilitation goals (see below). Work on emotional adjustment, cognitive strategies and skills, and communication was subsumed under the functional goal areas. For example, attentional skills were especially relevant to the leisure goal relating to watching films, whereas executive difficulties were particularly relevant to routine organization, and shopping and cooking skills. Regarding emotion, panic symptoms arose mainly when out in public, or in social situations. Increased stress and anxious arousal impacted performance in practical tasks. Her low self-esteem and social anxiety, in addition to disinhibition, impacted social situations, so work on developing awareness and skills in effective communication through group role-plays and video feedback was important groundwork for social relationship and leisure goals. Prior to rehabilitation, the engagement of a support worker to help with day-to-day tasks was suggested, but Judith was ambivalent about this, so, where appropriate, ability to self-advocate and seek appropriate support was raised when negotiating goals.

Judith's goals at the start of her programme were as follows:

1. Understanding about my brain injury – to demonstrate an understanding of the nature and consequences of my brain injury, and demonstrate effective strategy use to help me manage these difficulties.
2. Independent living skills
   - to identify a system for keeping track of things I need to do and the level of support required to implement this system
   - to have an understanding of the importance of pacing and fatigue management and be able to demonstrate this through a balanced weekly routine of activity, rest and relaxation
   - to identify the steps involved in ascertaining whether I am able to return to driving
   - with Pete to decide at the end of rehab (through improvement of skills and new strategies learnt) whether I could (with identified support) successfully fulfil a role of mother
   - to plan my meals on a weekly basis and formulate a recipe file including recipes that I feel confident (as rated by me) in preparing.
3. Recreational activities
   - to be engaged in identified physical leisure activities I am not currently undertaking on a regular basis.

Acceptance, adjustment and understanding

In working with Judith our evolving ideas about integrating 'meaning' and 'doing' (as described in the 'Y-shaped model', Chapter 4) were further applied and developed.

The process of rehabilitation differed significantly from that which might be suggested on the basis of an approach where emotional, cognitive and functional goals are worked on independently or in parallel. The traditional route would typically involve increasing

intellectual awareness, task analysis for main functional goals, identifying strategies and supports and hierarchical development of skills, strategy application and reduction of supports and finally generalization training as appropriate. Rather, to insure that our functional rehabilitation activity was integrated with the psychological formulation of 'threat to self', the following approach was used:

1. Collaborate on developing formulation of 'threat to self' with Judith in CBT sessions and joint CBT/occupational therapy (OT) sessions
2. Identify, carry out and build upon collaborative experiments to test out assumptions by dropping 'safety behaviours'
   - Carry out experiment and note behaviour and outcome in functional tasks or sessions
   - Reflect on outcomes in relation to unhelpful assumptions and predictions in CBT sessions
   - Review use of compensatory cognitive strategies in cognitive rehabilitation sessions
   - Co-ordinate next experiment in sessions with Judith and in team goal planning meeting
   - Carry out the next experiment etc.
3. Build new, adaptive self-representations, integrating consequences of TBI and strategies:
   - Identify past experiences (pre- and post-injury, including rehabilitation sessions where strategies were effectively used to gain positive outcomes) consistent with times Judith did not feel her identity under 'threat' and with a contrary meaning to current unhelpful view of self
   - Retrieve detailed, sensory recollections of these self-related experiences and identify related cognitions (such as assumptions about herself)
   - Build a 'positive formulation' or identity map around these, linking self-representations to concrete experiences, strategy use, and other resources
   - Identify further experiments or situations in which to consolidate positive self-representations, or affirm adaptive beliefs and assumptions
   - Collaborate on identification of support required to maintain and build on gains, applying 'traditional' rehabilitation approach with task analysis, graded practice, supported strategy use etc.

These steps are now described in more detail.

Collaborative formulation

The initial formulation (presented in Figure 17.1) was helpful in orienting the team to an understanding of Judith's underlying emotional world. However, the formulation was not constructed with Judith and was too complex to be presented to her in such a way as to promote her own understanding. The occupational therapist (OT) working with Judith on developing her memory and planning system for routine tasks and daily structure reported in goal planning that Judith had some obsessional worries about her ability to carry out tasks, leading to anxiety and checking behaviour at bedtime. The clinical psychologist joined the OT for a joint session with Judith to explore this issue and contribute to the development of a collaborative formulation. The specific aim of this was to find out what

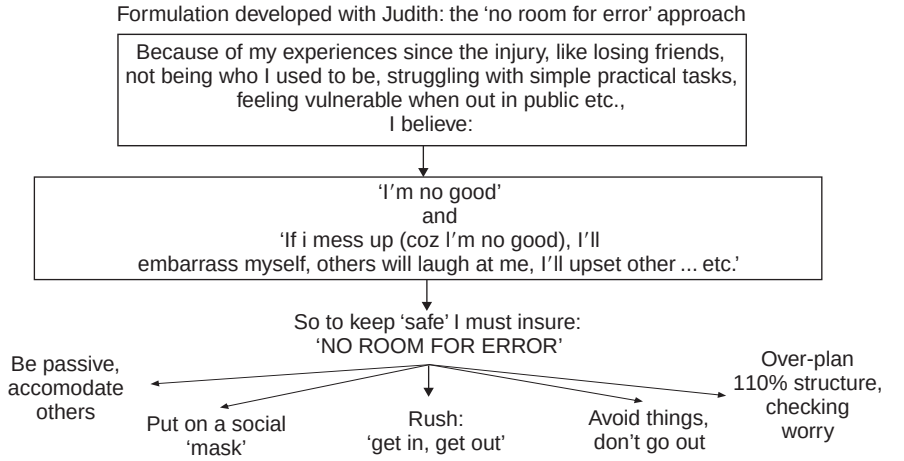
Formulation developed with Judith: the 'no room for error' approach
Because of my experiences since the injury, like losing friends, not being who I used to be, struggling with simple practical tasks, feeling vulnerable when out in public etc., I believe:
'I'm no good'
and
'If i mess up (coz I'm no good), I'll embarrass myself, others will laugh at me, I'll upset other ... etc.'
So to keep 'safe' I must insure:
'NO ROOM FOR ERROR'
Be passive, accomodate others
Put on a social 'mask'
Rush: 'get in, get out'
Avoid things, don't go out
Over-plan 110% structure, checking worry
Pros: safety, control, confidence, 'bastard injury not taking over my life', helps executive difficulties
Cons: False confidence, bastard injury does take over my life, reduced quality of life, no spontaneity in relationship ... Never learn I'm okay, good enough!!!

Figure 17.2 Initial collaborative formulation developed with Judith about her current anxiety, coping and ambivalence about change and used to develop a 'shared understanding' with the team.

the underlying core anxiety was for Judith, to clarify the role of possible 'safety behaviours' (such as checking) and find out about Judith's view of the pros and cons of her current coping (Moorey, 1996). Using guided discovery, Judith explained how constantly anxious she feels about making mistakes. She did not identify a single 'hot cognition' underlying her anxiety, but rather described a list of catastrophic outcomes including social humiliation, rejection and burdening her partner. An underlying belief about being 'no good' and the related 'there's no room for error' rule was identified as central, and as these themes emerged they were drawn out by the therapist, as shown in Figure 17.2 (the impact of cognitive consequences of the injury was omitted from the formulation for simplicity and clarity). Judith noted how this 'no room for error' rule was aimed at preventing the 'bastard injury' from running her life. She described a range of behaviours aimed at insuring that she was protected from any kind of 'mistake'. When Judith was asked to reflect on this formulation she tearfully recognized that her behaviours had such an impact that the 'bastard injury *is* taking over my life', perhaps reflecting the key 'hot cognition'.

Through this guided discovery and collaborative formulation Judith thus began to see how there was a mix of pros and cons to her current coping, and that to move forward it might be necessary to 'drop' some of her established safety behaviours. This led neatly on to the setting up of behavioural experiments.

Behavioural experiments

Behavioural experiments were used as the main approach to cognitive change in therapy with Judith. The key experiments set up in therapy are summarized in Table 17.1.

The initial experiment served partly as a means of socializing Judith to the cognitive model, highlighting the interaction of cognition, emotion and behaviour. Subsequent experiments evolved as the formulation of Judith's underlying sense of threatened identity

Table 17.1. Key behavioural experiments tackling cognitions associated with threats to self, including self-focused attention (experiment 1), negative social evaluation (experiments 2 and 4) and beliefs about cognitive impairments and disinhibited behaviour (experiments 3 and 4)

	Experiment 1: shifting attention	Experiment 2: dropping the 'mask'	Experiment 3: slowing down	Experiment 4: room for error?
Problem	Impact of self-focused attention on anxiety	Impact of social safety behaviours described as wearing a 'mask'	Impact of 'get in, get out' approach to shopping on anxiety and distraction	Not learning about the consequences of making an error due to high levels of obsessive planning in advance
Target cognition	'I must pay 110% attention to myself to keep in control'	'I must try to act chatty, funny, clever, or others will see there's something wrong with me'	'I'll get in a state of panic and swear at people so need to get out quickly'	'If I don't plan I'll make mistakes, others will think I'm a standing joke, it proves I'm no good'
Alternative perspective	'Paying attention to myself makes it harder to make sense of what's going on, I then get angry with myself and this makes my symptoms worse'	'Trying to be something I'm not makes me feel less like myself and more worried about the mask slipping, making me more anxious'	'Rushing makes it harder to focus on what I'm doing, feel less like myself, more anxious and so more likely to be disinhibited'	'Mistakes are acceptable, others won't judge me harshly, reject me and it is not a sign I'm no good'
Prediction	If the belief is true, then shifting attention will create problems If the alternative is true, I'll feel less anxious	If the belief is true then 'dropping the mask' I will make a fool of myself If the alternative is true, my behaviour will be okay, others won't laugh at me	If the belief is true, I will behave inappropriately if I do not rush If the alternative is true, not rushing will help reduce anxiety and disinhibited behaviour	If the belief is true, if I do something without planning I will make mistakes and others will be critical If the alternative is true, I'll make mistakes but others won't be critical and I might learn something useful from it

Experiment	1. Shift attention to topic in session when anxious 2. Try this when out with partner	Go to the gym without trying to act chatty Notice others' behaviour Ask rehab assistant to monitor your social behaviour	Go to supermarket with therapist Compare 'rushing' approach with 'slow' approach Note anxiety levels, ability to attend, sense of 'self'	Be asked to prepare an unfamiliar meal 'at the drop of a hat', video the task and ask others to rate, identify what learnt about cognitive difficulties, and rate 'room for error'
Results	Shifting attention away from self stopped anxiety from escalating, and social beha-viour was okay This was not possible in a noisy restaurant	Felt and appeared calmer, more relaxed Did not make a fool of myself Did not notice others reacting negatively or laughing	Rated less anxiety, better attention and less 'fighting with self' when not rushing Nearly snapped at someone when rushing	Managed task okay but made mistakes consistent with cognitive difficulties Others did not rate performance negatively, specific strengths and weaknesses identified to help with rehabilitation, increased rating that there is room for error
Reflection	Paying 110% attention to self does not help but exacerbates anxiety Impairments of attention mean that significant work in managing attention is required to apply this in busier places	I try to hide my injury with the 'mask' Maybe I haven't lost my 'self' I don't need to fight against it (the injury), don't need to put on a pretence	Need to not 'create events in my mind' but focus on the 'issue at hand' Slower approach was better Noticed fear of being trapped in busy aisle and need to keep looking for exit	Its healthy to make mistakes, I've got strengths and weaknesses but I'm okay Need to continue work on 'no room for error' – new goals: increase rating 'there is room for error' from 20% to 75%, and 'I'm able to be flexible with planning' from 5% to 65%

became clearer. Experiment 3 identified additional fears about being trapped and a need to be looking for exits at all times, which had not been identified in advance.

Judith extended her learning by attempting further experiments with support from Pete. She experienced partial success in reducing anxiety by shifting her attention away from herself when out for a meal with him. Following the 'supermarket' experiment, Judith set herself the task of going to a Moto GP (motorbike race) event with her partner. She successfully managed without having a panic attack by catching and not attending to the 'negative events created in my mind'. Reflecting on this, she noted feeling like her 'old self' for the first time since the accident, further evidence against the belief that she had 'entirely lost her old self'.

Of particular relevance to the restructuring of the 'no room for error' rule, was experiment 4, constructed and developed in conjunction with the OT working on the cooking goal and psychologist working on cognitive rehabilitation. Having developed the 'no room for error' formulation of her emotional adjustment, in a following CBT session Judith concluded: 'the no room for error approach gives me false confidence'. When asked how progress might be made on shifting this, Judith suggested:

'I need to just do something at the drop of a hat to find out if my fears are true.'

Following this, the psychologist and OT discussed how to set up her cooking sessions to provide the means of carrying out such an experiment. Ingredients were purchased and a recipe chosen and typed up for Judith, and the OT kitchen was made available to coincide with the CBT session. At the start of the next session, the therapist and Judith recapped from the previous session using notes and the formulation, and Judith once again stated her conclusion relating to the need to do something 'at the drop of a hat'. The therapist suggested that they could do this now, and Judith initially looked horrified, understandably. The therapist calmly described what was planned and clarified that there was no obligation, just that there was an opportunity to carry out the experiment if she so chose. The fact that doing this work would certainly increase anxiety prior to it diminishing was also clarified, this also being evident in the formulation from which the experiment was planned. Judith said that she did want to tackle this and would give it a go, despite her misgivings. The target cognition and alternative perspectives were clarified with Judith, the means of collecting data were discussed (video and observer ratings), and ratings of belief 'there is room for error' and 'I am able to be flexible with planning' were taken. As is often the case with experiments designed to tackle anxious predictions, Judith did experience increased anxiety, especially initially. The summary of the experiment (experiment 4) is presented in Table 17.1. This highlights how Judith was able to learn something new about her abilities, and despite initial increased anxiety learnt to be less fearful of social catastrophe, with reduced anxiety in the kitchen.

In short, this experiment paved the way for Judith to use compensatory strategies effectively based on an accurate appraisal of her difficulties based in experience, rather than overly rigid application of 'strategies' (aimed to maintain 'safety' but actually maintaining anxiety) in an obsessional manner with the aim of averting some feared catastrophe. Following feedback Judith re-rated her belief 'there is room for error' from 20% before the task to 80%. However, this shift was limited specifically to the cooking task. Judith set herself the goal of increasing her 'room for error' belief rating from 20% before the task to 75% across situations. The unexpected learning from this task was that Judith saw how, rather than anxiously trying to think about and use strategies for everything regardless, she could learn more about her strengths as well as weaknesses by taking such 'risks'. Practical

tasks such as cooking began to be appraised by Judith as opportunities for learning rather than potential threats to a vulnerable sense of identity.

These experiments and associated reflective learning were drawn upon to support the development of a constructive, adaptive or 'positive' formulation.

The 'positive formulation'

As noted above, Ylvisaker and Feeney (2000) have described a constructive approach to rehabilitation involving the creation of 'identity maps' with clients, which can be drawn upon to guide affect, communication and behaviour in specific contexts, tasks or situations. The approach they describe bears a similarity with a creative approach to working with clients with recurrent mental health problems presented by Mooney and Padesky (2000). Both approaches include use of metaphor or identified 'icons' ('heroes' or admired characters) to characterize a set of previous experiences that carry a meaning contrary to that which is associated with maladaptive coping. For example, Ylvisaker and Feeney describe their client 'Jason', and how a negative self-image of 'Jason as victim' was identified and an alternative self-representation of 'Jason as Clint Eastwood' was developed, which integrated positive or adaptive characteristics and strategies.

Mooney and Padesky's CBT approach aims to shift unhelpful rigid or absolute underlying assumptions and build new, adaptive assumptions and rules. There are a number of techniques employed through the process, including identification of an experience in which the individual felt different, or felt they had qualities that are opposite to those represented in the problem formulation. When activating positive affective states, Mooney and Padesky suggest mirroring and exaggeration of the client's positive affect. For example, if the client sits forward, and begins to smile as describing a good experience, the therapist also sits forward, and engages in exploring this positive experience, to deepen the affect and share in the feeling with the client. Imagery can be a powerful way of supporting clients to access a richer, affectively 'warm' account of such experiences. The next step is to work with the client identifying skills, meanings and rules or assumptions associated with this state. The client is asked to provide a label or name for this state or aspect of themselves. Synthesizing questions are used to support the client in wondering what the problem situation might be like if they were to bring to it the rules, principles, demeanour, feelings, assumptions and behaviours or skills of the person they were in the positive experience. Finally, from this the next step is to ask the client how he/she might want to test out the new learning or assumptions. Positive or constructive behavioural experiments aimed at building on the new, positive or alternative meaning are then carried out to consolidate this new aspect of identity through activity.

Through rehabilitation and the specific experiments described earlier, Judith began to find new experiences and meanings in previously avoided situations. At this stage, in terms of the Y-shaped model we presented in Chapter 4, it could be said that Judith had achieved a degree of safety, and was beginning to approach 'integration' of at least some pre- and post-injury self-representations. However, in our approach, identity work requires active support to explore, find and develop new meanings, and then consolidate these in day-to-day life. So a further step is required following the problem-focused work. Both pre- and post-injury positive experiences were drawn upon to develop new, emotionally and personally significant meanings representing some continuity with pre-injury self. These were then used in consolidating changes and integrating these into a new post-injury sense of identity.

First of all, having successfully managed to go to the busy Moto GP event without panicking, Judith was able to use an image of herself in this situation when she felt she coped especially well as a way of 'challenging' her intrusive anxious images in other situations. Judith had also taken 'risks' in the programme, such as participating in a role-play in the communication group, and developing mutually supportive relationships with her peers within the milieu of the programme. We then turned to the development of a new, adaptive meaning. When asked to think of a time when she did or experienced something contrary to her current anxious, unconfident state, fearful of errors and humiliation through failure, Judith was able to recall a key moment. Having identified the memory, she began to smile and explained about an incident during her motorbike-riding lessons. She was developing her skills on a large machine, and her male instructor had teased her that, being a slightly built woman, she would be unable to complete a U-turn on a narrow stretch of road. The challenge having been made, Judith recounted how she focused her mind, controlled the bike round, then triumphant, opened up the throttle, 'flicking the V's' (a non-verbal gesture popular in the UK, seen as offensive and defiant) at him as she drove off. As she finished the story she laughed, and we explored the sense of fulfilment and achievement she had.

After this work, getting a good detailed account of the feeling, Judith was asked to think about where this feeling fits in her life post-injury. She was able to connect this feeling with some of her experiments and small successes in rehab. From this we began to construct a positive formulation Judith chose to call the 'U-turn approach', and this is presented in Figure 17.3. The key meaning from these experiences, consolidated in new experiences and experiments, was 'I *am* a someone after all'. Having established that not all was lost in the injury, Judith became more able to draw on her awareness of strengths and weaknesses, and strategies and skills developed elsewhere in rehabilitation, to note the ongoing difficulties she has, and the ways she can manage these.

In this way, by the end of the programme, Judith's understanding of her injury, strategy use, sense of identity and engagement in meaningful functional activity had developed significantly. Developing a shared understanding through facilitated, collaborative exploration and experiment ensured rehabilitation was synchronized between Judith and the team, and that rehabilitation tasks fell in the 'zone of proximal development'. Judith was able to move towards a more integrated sense of herself, and accept the support required to maintain and consolidate gains in her own community post-rehabilitation, including making arrangements to employ a support worker to enable her to continue to work on increasing her independence.

Outcomes

Questionnaire measures

Psychosocial outcome in terms of perceived symptom and behaviour change was assessed prior to, during and following rehabilitation using the European Brain Injury Questionnaire (EBIQ; Teasdale *et al.*, 1997). This is shown in Figure 17.4.

Self-ratings show a clear drop in perceived occurrence of problems maintained for the follow-up year. However, her partner's ratings indicate some deterioration in the initial three-month period post-rehabilitation.

Similarly, self-ratings of executive problems on the Dysexecutive Questionnaire (DEX, from the Behavioural Assessment of the Dysexecutive Syndrome, BADS, Wilson *et al.*,

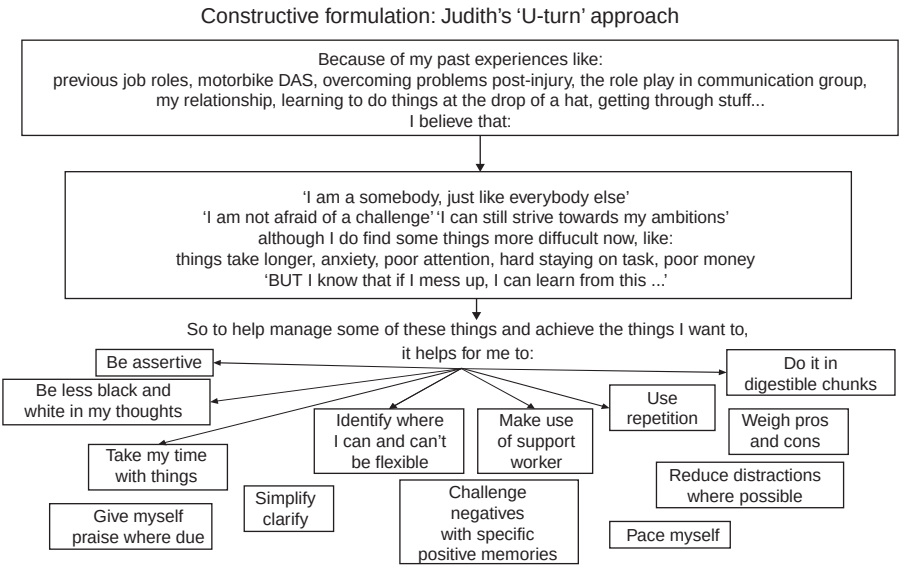
Constructive formulation: Judith's 'U-turn' approach
Because of my past experiences like:
previous job roles, motorbike DAS, overcoming problems post-injury, the role play in communication group,
my relationship, learning to do things at the drop of a hat, getting through stuff...
I believe that:
'I am a somebody, just like everybody else'
'I am not afraid of a challenge' 'I can still strive towards my ambitions'
although I do find some things more diffucult now, like:
things take longer, anxiety, poor attention, hard staying on task, poor money
'BUT I know that if I mess up, I can learn from this ...'
So to help manage some of these things and achieve the things I want to,
it helps for me to:
Be assertive
Be less black and white in my thoughts
Take my time with things
Give myself praise where due
Simplify clarify
Identify where I can and can't be flexible
Challenge negatives with specific positive memories
Make use of support worker
Use repetition
Pace myself
Do it in digestible chunks
Weigh pros and cons
Reduce distractions where possible

Figure 17.3 Positive formulation developed with Judith to represent alternative, adaptive aspects of her identity and to support consolidation of gains through further constructive experiments. DAS = 'Direct Access Scheme' motorcycle training (for a licence to ride bikes larger than 500 cc).

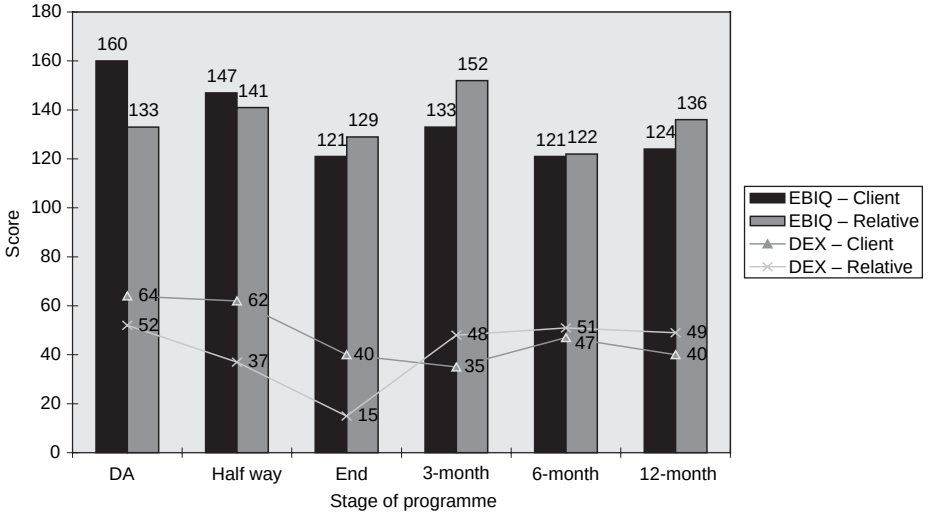

Figure 17.4 Changes in ratings of Judith's symptoms and behaviour made by herself and her partner Pete before rehabilitation (DA: detailed assessment), at the half way point in the programme (i.e. 12 weeks), end of programme (i.e. 24 weeks) and at three follow-up points.

1996) showed clear improvement during the programme with some variability over the year post-rehabilitation, although it appears on this measure that some gains have been maintained. Her partner's ratings were less positive, indicating perceived occurrence of executive problems to have increased.

Goal attainment

Judith achieved or partially achieved all her rehabilitation goals. Of particular relevance to the evaluation of the work described in this chapter are the following goals:

- To demonstrate (through self-rating and dropping safety behaviours such as avoidance and rushing) that I can engage in four specified functional activities with minimal levels of anxiety (to include supermarket shopping, cooking and public transport).

This goal was achieved at the end of her six-month programme, and following the programme Judith set herself further goals to develop cooking skills at home.

- To plan my meals on a weekly basis and formulate a recipe file including recipes that I feel confident (as rated by myself) in preparing.

This goal was partially achieved at the end of the six month programme, as Judith had created a file containing some recipes in an adapted checklist form, but was not routinely planning all her meals on a weekly basis.

Reviewing her progress at the end of the programme, Judith reported that she'd achieved her personal objectives regarding emotional adjustment and so felt she was able to:

- '… not have to wear a mask or pretend to be something I am not'
- 'stop criticizing myself to the extent I do', and
- '… control the phobias I have about being outside alone'

From our reviewing of Judith's situation over a year post-programme we observed that she was maintaining functional gains in those areas worked on in rehabilitation. She also continued to have a more positive orientation to her identity and future potential. Not all of these gains effectively generalized to other areas. For example, her PTSD symptoms continued and further psychological therapy was sought to address these.

Conclusion

Judith was supported to discover and reappraise her strong negative self-perception and fearful predictions and assumptions about life post-injury through development of a shared understanding and interdisciplinary behavioural experiments. These experiments systematically linked doing and meaning in her rehabilitation programme. On formal measures of the occurrence of symptoms relating to brain injury, her partner's ratings of her showed initial improvement with some slip back over the year after her programme. Although it was not measured formally, in our view and Judith's she became better able to look upon herself post-injury without a strong emotional reaction. One could argue that she had a more accurate and adaptive view of herself by the end of the programme and so had reduced her self-discrepancy, her sense of 'constantly being in a battle' with herself. Previously anxiety-provoking situations became seen by Judith as learning opportunities. Behaviourally this adaptation was observed in the attainment of specific functional goals, the reduction in verbally aggressive and disinhibited behaviour during the programme, the uptake of appropriate strategies, and the acceptance of a support worker post-programme. The need for long-term support to maintain and generalize gains is also highlighted by this case.

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Chapter 18

Simon: brain injury and the family – the inclusion of children, family members and wider systems in the rehabilitation process

Siobhan Palmer, Kate Psaila and Giles Yeates

Work with one client, Simon, and his family is described here in order to illustrate the importance of considering the individual in the context of his/her relationships, family systems and the wider systems of agencies involved in clients with brain injuries. This wider perspective supports rehabilitation in a number of ways. Consideration of these systemic factors, such as the impact of changes achieved in rehabilitation on family members (Perlesz *et al*., 1999; Laroi, 2003) and the involvement of, and interchange of information with, other agencies, is increasingly recognized as important to the achievement of rehabilitation goals. A client-centred approach is important in the development of a collaborative relationship both with the injured person and their family members (Sohlberg *et al*., 2001). Further, understanding the social and personal contexts of the person with the injury, including the influence of wider systems, is important in formulating and developing appropriate interventions (Wade, 2005). When significant others support the rehabilitation process, this reduces the likelihood of opting out (Oddy and Herbert, 2003).

Through the account of our work with Simon, we illustrate how understanding relational issues was crucial to the timing and types of intervention offered and ultimately in enabling Simon to work towards his goals relating to parenting. The chapter will summarize the presenting problems and results of the detailed assessment before offering a description and discussion of the approach taken toward this work, including a description of intervention.

Introduction

History of injury

Simon was referred for rehabilitation when he was 37. Twenty months prior to starting rehabilitation, he had been admitted to hospital due to a haemorrhagic stroke understood to have been a secondary consequence of a hereditary condition, haemorrhagic telangiectasia.

Neuropsychological Rehabilitation: Theory, Models, Therapy and Outcome, Barbara A. Wilson, Fergus Gracey, Jonathan J. Evans and Andrew Bateman. Published by Cambridge University Press. © B. A. Wilson, F. Gracey, J. J. Evans and A. Bateman 2009.

Following initial discharge from hospital after the haemorrhage, Simon was readmitted a week later when a left fronto-parietal abscess was discovered. This abscess was drained and Simon was in a coma for three weeks. He was finally discharged home two months later.

Social history

Prior to the assessment for rehabilitation, Simon and his wife, Jane, had a period of separation. However, at the time of assessment he lived with Jane and their three children Ed, Toby and Fiona. Simon was employed as a foreman and groundworker in a civil engineering firm, supervising four employees. When assessed at the Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation he remained on sick leave from work, and his job remained open for him. He used to enjoy socializing in a local pub with friends. He described that prior to the stroke he enjoyed working on home improvements, remote control cars and going out with friends.

Assessment process

Simon attended the Centre for an initial one-day preliminary assessment and subsequently for an eight-day detailed assessment. When Simon presented for preliminary assessment, he reported problems with reading, writing, memory, vision, concentration and right-sided weakness. At this time, his wife reported 'motivation' to be an additional problem because Simon would rarely engage himself in tasks around the house; something that was a change from pre-injury.

Below is a summary of findings following the detailed assessment.

Initial goals

Simon identified the following goals that he would like to achieve:

- To improve reading and writing
- To be able to 'get words out'
- To return to work as foreman and groundworker
- To get driving licence back
- To feel more like his 'old self'.

Neuropsychological assessment

Testing identified a number of areas of impairment and difficulty, as well as some strengths. Simon performed well on several tests of attention including those for divided, sustained and auditory selective attention. However, visual selective attention was impaired. Simon had difficulty identifying objects, recognizing faces and emotions, and making social judgments. A tendency to compress the right-hand side of space in constructional tasks was evident. Tests of executive function identified difficulties with planning, goal management and perseverative thinking. Memory difficulties in some contexts also had an impact on functional performance. On assessments of working memory, he scored in the low average range.

Language and communication

Simon had significant speech and language difficulties. He had mild dysarthria, and higher level language difficulties including word-finding problems, dyslexia and difficulty understanding written language beyond sentence level. His memory and problem solving difficulties also impacted on his language.

Adjustment, mood and behaviour

Simon identified no emotional difficulties other than social anxiety in pubs (about offending people if he were to bump into them), which was secondary to hemianopia. He coped with this by avoiding pubs where possible. He noted some experience of depression, irritability, mood swings and reduced motivation since the injury, which was managed to some extent with medication. Both he and his wife identified relationship difficulties as being a significant issue in the past. This had culminated in a six-week separation. However, when Simon resumed his antidepressant medication, Jane and he started living together again. However, Jane noted emotional changes to be a continued source of worry, which culminated in a permanent separation after the detailed assessment and prior to the beginning of the rehabilitation programme.

Simon described several coping strategies, although difficulties with accessing emotional experience and with future problem solving were identified as challenges to emotional adjustment.

Functional implications

Although Simon reported his memory was not as good as prior to his stroke, he denied any significant functional consequences and did not anticipate difficulties returning to work, although he acknowledged that he may benefit from a graduated return.

From observations and assessments undertaken, it was considered likely that Simon did not fully anticipate potential practical consequences of impairments and was not, therefore, in a position to develop necessary strategies to manage these. Therefore, outreach support to address functional difficulties within the home and work context was recommended.

Simon's wife, Jane, and his mother-in-law, Joyce, attended the summary of assessment meeting at the end of the eight-day assessment. The impact of neuropsychological impairments, restricted vocational activity, altered mood and relationships with his family members were key concerns. Jane and Joyce were keen to support Simon and to be involved in the rehabilitation. They also identified particular difficulties that arose as a result of Simon's low awareness and were keen to help him adjust to the new situation.

Summary

In summary of the above assessments, it was concluded that Simon's persisting difficulties were as follows:

Impairments

- Right-side visual deficit and suspected mild right neglect
- Decreased dexterity in right upper limb
- Limited awareness of cognitive impairments
- Slow speed of processing
- Difficulty with reading comprehension, and writing
- Impaired immediate and delayed memory
- Impaired visual selective attention
- Difficulty with identifying objects, possibly secondary to both visual processing and semantic access problems
- Deficits in identifying (especially negative) emotions, from facial expressions
- Impaired executive function, including poor planning, implementation, self-monitoring and impulse control.

Activity and participation restrictions

- Unable to drive
- Currently unable to work
- Difficulty interpreting social situations and making social judgments
- Difficulty planning, and decision-making in domestic tasks, i.e. shopping
- Difficulty remembering and scanning for the location of objects
- Decreased confidence in social environment, i.e. pub
- Difficulty with manipulating fine objects with right hand
- Relationship difficulties
- Currently requires antidepressants to manage low mood.

Formulation

Prior to the injury, Simon described himself as an 'easy-going guy who was respected by his friends, employers and those work colleagues who he supervised as foreman'. Prior to the injury he explained that he coped with difficult emotions by distracting himself through activity, a style that he continued to use. Since the injury, his wife described him as 'Jekyll and Hyde' in reference to his changeable and volatile mood, which they both acknowledged. It was of note that Simon had difficulty with noticing what he needed to cope with, and was helped by other people drawing attention to these issues.

Initially, the emotional lability described was formulated as a direct result of the depression as opposed to the stroke. During periods of depression, Simon reported a growing detachment from his wife. However when his wife left, he reported that this departure took him completely by surprise and made him feel hurt and angry; supporting the formulation that Simon needs support to notice problems or anticipate potential difficulties. It was proposed that the ongoing dispute between Simon and his family regarding the significance or presence of difficulties resulted in tensions within the relationships, which were difficult to talk about or resolve between them. Significant losses (of job and health), coupled with confusion about abilities (such as reading and problem solving) and avoidance, were likely to maintain the anxiety and irritability. Simon's anxiety, irritability and avoidance could be formulated as what Ben-Yishay (2000) described as a 'catastrophic reaction' to threats to his identity and sense of autonomy resulting from changed roles, changed abilities and confusion about reduced success in activities or relationships where changes, which he 'didn't see coming' seemed to happen suddenly. In the context of the catastrophic reaction, and relationships that no longer felt safe, it was proposed that acknowledging difficulties was very threatening for Simon. Poor understanding about his injury that resulted in misattribution of cause of difficulties, or a reluctance (or inability) to access emotional experience, was likely to maintain the anxiety, sense of personal threat and present a challenge to adjustment. Subsequently, when difficulties arose or there were reminders of change, Simon was likely to become irritable or angry.

Recommendations

It was recommended that Simon have speech and language therapy, clinical psychology and occupational therapy input, both in the Centre and in his own environment. The purpose of this individual intervention would be to:

- Work through relationship issues: talking about different perspectives and make sense of his experiences since the stroke.

- Trial cognitive strategies: discovering 'ways around' difficulties, which might make it less threatening to acknowledge them.
- Investigate vocational options, and work site assessment.
- Increase Simon's understanding of his injury and its consequences in order to support him to predict potential challenges in advance.

These recommendations were discussed with Simon who said he was keen for this input.

Post-assessment goals

Following the detailed assessment, Simon's family circumstances changed; he and his wife separated, which influenced his decisions about the goals he chose to work on during rehabilitation. At the beginning of the programme, six goal areas were selected as follows:

1. Understanding the injury and its consequences, and managing these effectively
2. Independent living skills such as budgeting, planning and managing correspondence and finances
3. Identification of a realistic vocational action plan for the forthcoming 6–12 months.

In addition to these areas, Simon also set three goals relevant to parenting and relationships:

4. Simon will be confident in his ability to read short stories to his two younger children as rated by speech and language therapists (SLTs) and evaluations of two independent raters
5. Simon will undertake specified parenting roles independently (including being 'planful' in arranging their day-to-day activities, supporting them in completing homework and engaging in leisure activities)
6. Simon will interact more successfully in identified social interactions as rated by himself, his carer and staff at OZC.

Following the assessment, he returned for the 24-week rehabilitation programme.

Rehabilitation programme

During the first 12 weeks, Simon attended the intensive programme at the Centre four days per week. During this time, he attended the different groups detailed elsewhere (Cognitive, Understanding Brain Injury, Mood, Communication, Newsletter, Leisure) as well as individual sessions with occupational therapists, SLTs, clinical psychologists and rehabilitation assistants.

In the integration phase of the programme, the second 12 weeks, Simon wanted to focus on goals related to his children and independent living. He held these in high priority and particularly wanted to focus on parenting skills and leisure activities involving his children. He attended the Centre two days per week for this phase. The other days were spent focused around work and opportunities for spending time with his children, in order to ensure effective generalization of gains made whilst at the Centre.

The aim of this chapter is to describe the family interventions and the approach to thinking about the influence of wider systems, which complimented and supported the rehabilitation. As this work was part of an interdisciplinary programme, it is important to be aware of the other goal areas described above, but work on these goals will not be described in detail.

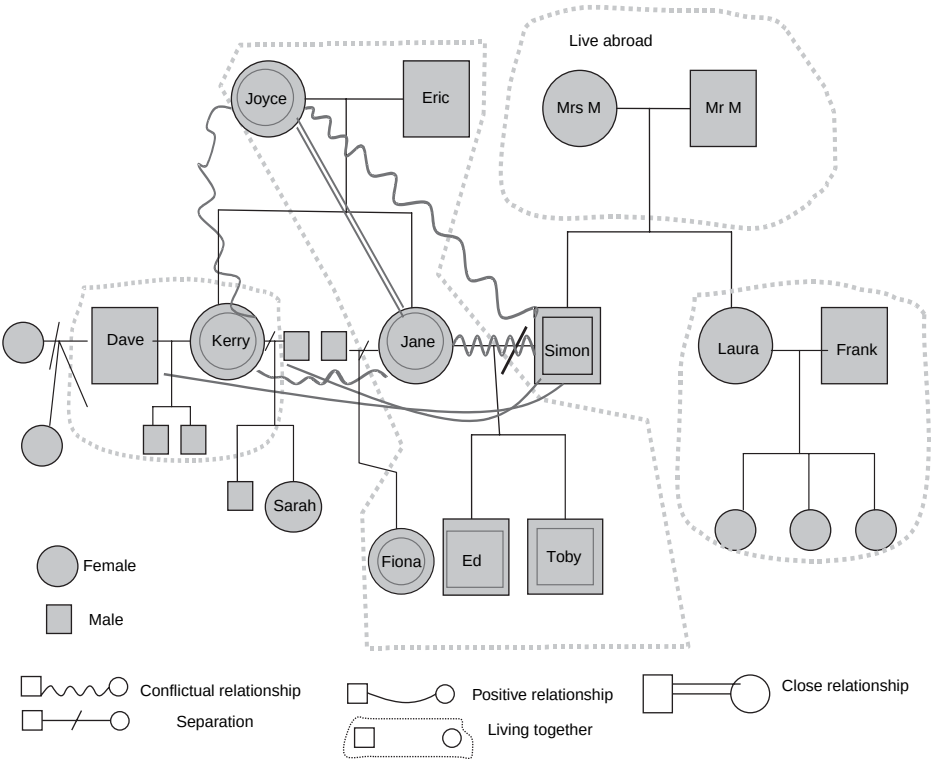

Figure 18.1. Genogram illustrating significant family relationships. See also colour plate.

Family work

Background and assessment

The assessment and knowledge of background information was developed over the whole period of time that Simon was in contact with the Centre. His family situation changed rapidly and this constantly influenced the work that Simon was engaged with in rehabilitation. The background information was collated through discussions with Simon in the Centre, regular telephone conversations with Kerry (Simon's sister-in-law), irregular telephone conversations with Jane and a number of telephone conversations with a family therapist involved in his treatment, in addition to family sessions at the Centre. Over the course of Simon's programme, there were a multitude of variables, which were important to consider in the context of his rehabilitation.

Relationships

Historically there were a number of conflicts and narratives within the family, which influenced Simon during his rehabilitation. These relationships are illustrated in Figure 18.1.

The recent separation between Simon and Jane was not amicable; there were a number of tensions and disagreements, particularly around contact with the children, money and the house, divorce papers and Jane's new partner. Jane reported that she had found the

whole experience very difficult. She reported that she had said goodbye to Simon in the hospital when they were told that he was going to die. When he returned home she found him angry and aggressive, and said this was difficult to deal with – particularly as she was concerned about the children. At the detailed assessment, Jane reported feeling suicidal, though with no intention to act upon the feeling.

Joyce also expressed concern about the children's safety, particularly in terms of Simon forgetting what they were doing when he was looking after them. She reported that she never held Simon and Jane's parenting skills in high regard prior to the brain injury. She described them as 'putting the children after themselves', and her perspective of Jane and Simon's parenting continued following their separation. Kerry took a caring role, and Simon moved into her home temporarily. Joyce questioned Kerry's motives for 'caring' for Simon, and said that she did not understand why he needed any support. Kerry reported that she started caring for Simon because he didn't have anyone else, and it was in her nature to help out people in need. Kerry and Joyce had a conflictual relationship; Kerry's perspective was that Joyce favoured Jane and 'molly-coddled' her. Kerry felt that Joyce had 'too much of an influence' on what happened to Jane's children. She also described being upset that Joyce paid more attention to Jane's children than her own.

There was a long-standing tension between Kerry and Jane. Unfortunately, they had a disagreement and ceased talking to each other over another family matter for a number of months. At this time, the relationship between Kerry and Joyce also deteriorated further and Jane did not want her children to have any contact with Kerry.

The children's perspectives were not described strongly in the narratives of the adults. There was some concern for the children's safety whilst in Simon's care, from Jane and Joyce and they asked for some help in explaining Simon's brain injury to the children. In particular, they hoped to explain to the children some of the reasons why Simon was different.

Housing

Initially, when Simon and Jane separated, Simon moved from the family home to Kerry's overcrowded house. Simon and Jane agreed to sell the family home in order to clear their debts, although there was a possibility that the house would be repossessed before it was sold. There was a period of time where Simon had moved back to the family home (without prior agreement from Jane), and Jane and the children moved in with her mother (Joyce). Shortly afterwards, whilst Simon was away, Jane cleared the family home of all possessions, which was a shock to Simon when he returned. After the house sale, Simon was homeless and offered bed and breakfast accommodation. This would have meant moving frequently, and would have interfered even more with his contact with the children. This situation was unpreventable, and although the housing organization was warned about this in advance, they were unable to do anything until he was actually made homeless. Thus, he moved back with Kerry temporarily until eventually at the end of the rehabilitation programme he was moved into his own accommodation nearby.

Contact with the children

Simon and the children initially saw each other regularly when he was staying with Kerry. Kerry facilitated contact by collecting the children, providing a venue for them to meet and dropping them home again. During this period Jane and Simon were not communicating with each other.

During the time when Kerry and Jane were not communicating, Jane reported that she did not want the children to be in contact with Kerry. Although she said she was happy for

them to see Simon, this was a practical impossibility as he had no transport without Kerry's support and nowhere else to see them if not in the family home or at Kerry's house.

When Simon moved back into his house and Jane and the children moved in with Joyce, Simon had no contact with the children at all. The family began to see a family therapy team in a Child and Adolescent Mental Health Service due to behaviour problems with one of his children at school.

Other services

Simon was also involved with other agencies as described below.

Headway

Simon had some support from a Community Support Worker from Headway (the main charitable support organization for people with head injuries in the UK). Her main role was to advocate for him and assist him in gaining access to services he needed. She was supportive of Kerry, and reinforced her perspective of the situation. Simon also attended Headway for several sessions.

Social Services

Simon was allocated a Social Worker from the Physical Disability Team. An additional referral to Social Services was made to assess risk with regards to the children. Social Services assessed the situation and were not able to offer any intervention on parenting skills as they had concluded the children were not at risk.

Personal injury lawyer/solicitor

There were two main roles of the solicitor, the initial one was with regards the divorce settlement, and the second was around access to the children. Both these cases were ongoing throughout our contact with Simon and his family. Liaison around Simon's cognitive difficulties was essential with the solicitor in terms of providing him with the support he needed in court, and with any assessment carried out in relation to his contact with the children.

Family therapy

During the period that we were not working with the family, and Simon had very little contact with them, he learned that they were attending family therapy sessions in a local National Health Service Child and Adolescent Mental Health Service. Although not present in these sessions, he was often talked about, and they were interested in his attendance at a future date.

OZC staff

There was some frustration within the team, and from Simon and his supportive network, that he did not have the environment that provided opportunities to progress on his personal goals. The goals that were most affected by these limitations were in the area of activities of daily living, including parenting. It also had an impact on short-term goals particularly related to his cognitive work, which involved him wanting to help his children with their homework, and his mood and adjustment work, which involved parenting skills.

Assessment

In addition to the less formal continual assessment of the situation, three more formal assessment periods were arranged. One of the first contacts that Jane and Simon had with each other following their separation was a couple session at the Centre. They both reported

feeling apprehensive about this. One aim of this session was to find out what type of family work the couple wanted and who should be involved from their perspective. They had wanted the first meeting to be without the children, so that they were not brought into the difficulties. They also maintained that they did not want any Couple Therapy, and that any intervention was to be focused on the children. The couple discussed how to take this forward in the session.

The second assessment session involved Jane, Simon and the three children – Fiona (age 12), Ed (aged 8) and Toby (aged 7). The aim of this session was to hear the perspectives of the children, and find out what they wanted to find out about, particularly in relation to understanding the brain injury. This consisted of educational games previously suggested for acquired brain injury (ABI) work with child relatives (Webster *et al*., 2003a).

Following this session there was a break of five months, where many factors had changed and the family had been engaged with local child family therapy services; at this point reassessment of the situation was crucial. The primary therapist liaised with the family therapy services initially through a letter outlining a meta-perspective of cross-service involvement, acknowledging the presence of overlap in our respective conversations and raising curiosities about helpful cross-service conversations in the future, with differing in-session family arrangements to support these conversations. The primary therapist also spoke individually with Joyce, Jane, Simon and Kerry, before they were all invited to a family meeting. They agreed that it was important that they were all invited to the session with the children.

Reformulation

The information was formulated using a biopsychosocial model (consistent with the approach outline in Chapter 1, Evans (2006) and White (2005)), with particular attention to the influence of systemic factors in maintaining conversations (see Figure 18.2). Throughout the assessment period the different perspectives of individual family members were noted. The sharing of these perspectives between some family members highlighted the divisive nature of these ideas. For example, the children expressed their concerns that when Simon forgets to phone them it is because he does not love them. Joyce and Jane expressed their concern that the children were unsafe in Simon's care, and Kerry and Simon's perspective that this was unfounded was highlighted in response. Some of the perspectives shared seemed to be maintained by confusion and misunderstandings about the consequences of ABI.

All of the adults involved seemed to be concerned about how the children had made sense of their experiences, and behavioural change at school had clearly engaged their concern. In particular, they noted distressing experiences of meeting their father in hospital, seeing him on a ventilator and being told that he might die, and then experiencing him as very different afterwards. A shared hope to support the children and consider their needs was the one factor that brought together this group of adults who were divided on so many other issues.

The children had different opinions on how their Daddy was after being in hospital. Toby said Daddy is 'completely better', Fiona said he needs 'some things fixing' and Ed said he was 'definitely not better'. 'Reading' and 'not being naughty' were identified as things to work on, with a detailed account by Ed and Fiona of Daddy shouting at Mummy and her boyfriend in the pub. The children described their father in four different stages:

- pre-injury
- in hospital

- Jekyll and Hyde
- now.

It was hypothesized that the discrepant stories told within this family were, in part, the consequence of a traumatic event affecting the whole family system in which there was premorbid culture of blame and beliefs about protecting children from difficult stories. As suggested earlier, the different stories may be somewhat maintained by common misconceptions about brain injury (Hux *et al*., 2006) and predominantly avoidant family coping style. The consequences of Simon's difficulties with social cognition and with impulse control were likely to be misunderstood and attributed to his being a 'completely different' person rather than as understandable consequences of his injury. Additionally, the response of the family to Simon's acquired difficulties is likely to have perpetuated his frustration and own misunderstanding of the situation, thereby further compromising his cognitive abilities. It was hypothesized that the emotion in the family may be expressed through the children's behaviour and this is why the children were presented as those who need the most help and support. Further, it was hypothesized that different perspectives would also be held between services, which could contribute to maintaining different conversations within professional and family systems. This is illustrated in Figure 18.2.

Intervention

The main focus of intervention was to construct a shared understanding of the consequences of brain injury and the impact this had on the family, and the stories told within the family. This was done in a number of ways through psychoeducation work with the children and a sharing of perspectives between different systems: within and between services, between services and the family and between the adults and the children in the family. A summary of interventions is presented in Table 18.1. Indirect interventions included:

Mapping the problem-determined system(s) (Anderson *et al*., 1986) and eco-mapping (Hartman, 1995)

The essential first step, and the first unique contribution of OZC to Simon's wider context of family experience and service involvement, was to map out all family relationships and problem-definitions within these using techniques, such as genogram annotation and interview (Petry and McGoldrick, 2003). This was also done for existing services who were involved, the nature and focus of their involvement with differing members of Simon's family, and making explicit the meanings, premises and problem definitions inherent in these relationships. Service gaps were intentionally located following the recommendations of Hartman (1995). Using the new information and emerging perspectives from this exercise, all existing and new rehabilitation interventions (individual and family) could be placed within particular and changing frames of meaning for differing system members.

Liaison with other services

The second intervention was the liaison with the family therapy service. Simon and Kerry were the only two family members we had contact with for a number of months; thus maintaining the divide between conversations. Simon first heard that the rest of the family were going to family therapy sessions, when he was invited to one of them. In response, a therapeutic letter was written to the service and the family offering to liaise with the family therapy team, or to join the reflective team for a session or more. This letter was sent to everyone involved.

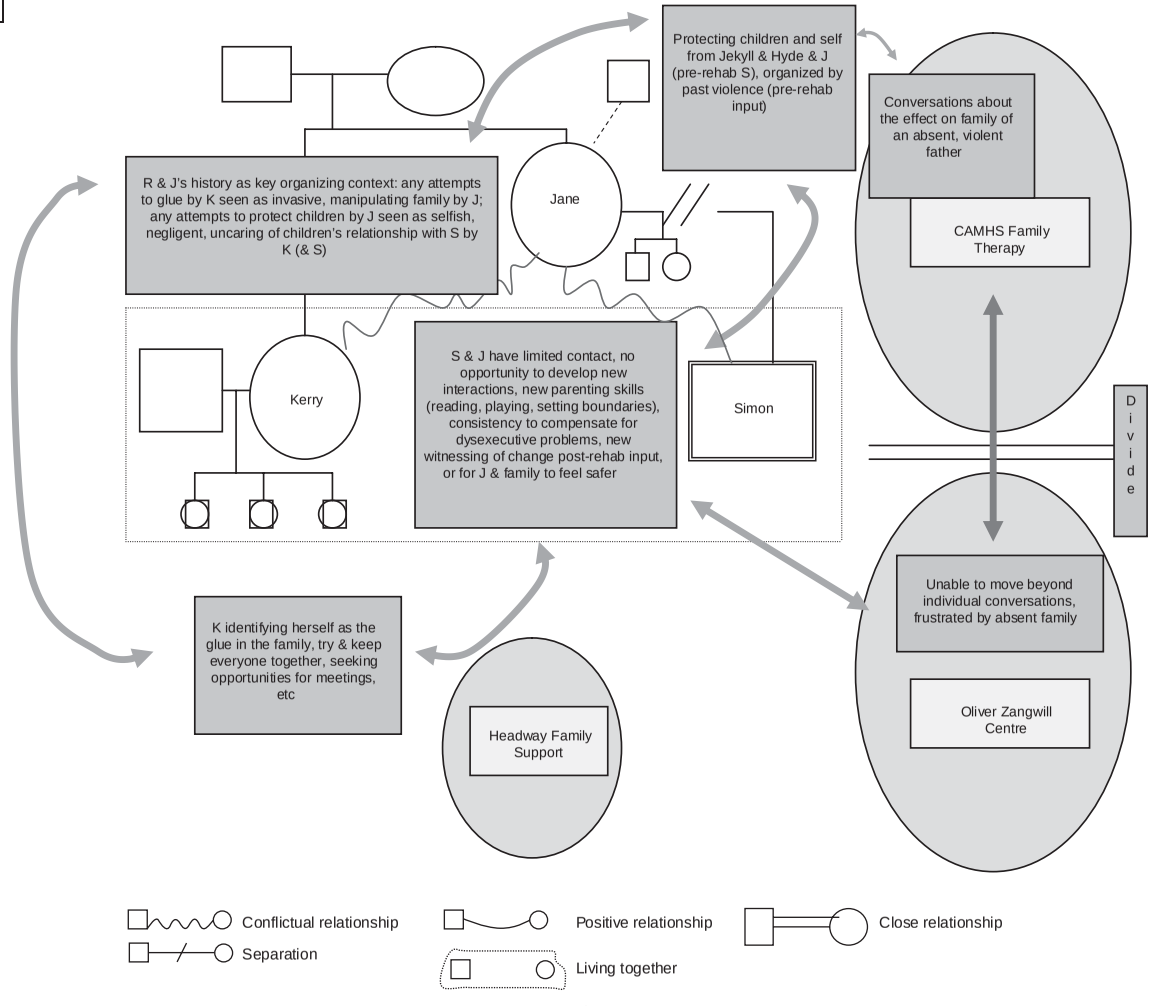
Protecting children and self from Jekyll & Hyde & J (pre-rehab S), organized by past violence (pre-rehab input)
Conversations about the effect on family of an absent, violent father
CAMHS Family Therapy
R & J's history as key organizing context: any attempts to glue by K seen as invasive, manipulating family by J; any attempts to protect children by J seen as selfish, negligent, uncaring of children's relationship with S by K (& S)
Jane
Kerry
S & J have limited contact, no opportunity to develop new interactions, new parenting skills (reading, playing, setting boundaries), consistency to compensate for dysexecutive problems, new witnessing of change post-rehab input, or for J & family to feel safer
Simon
Divide
Unable to move beyond individual conversations, frustrated by absent family
Oliver Zangwill Centre
K identifying herself as the glue in the family, try & keep everyone together, seeking opportunities for meetings, etc
Headway Family Support
Conflictual relationship
Separation
Positive relationship
Living together
Close relationship

Figure 18.2. Genogram and eco-map highlighting the system of relationships, communication and meanings around Simon.

Table 18.1. Summary of family interventions

Session	Topic	Present	Main points
1	Couple assessment	Jane & Simon	• Establishing a common ground • Constructed as parental experts providing a link between OZC and children • J & S agreed to speak to children about immediate issues only
2	Family assessment and psychoeducation regarding brain injury Liaison Telephone conversation with family therapist	Jane, Simon, Fiona, Ed, Toby	• Brain functions (look at model of brain) • What happened to Daddy? (draw) • What do the children want to know about? • How Daddy is doing some things differently (ABI & rehab strategies) • What is Daddy doing at OZC? • How is he getting on? • Sharing of perspectives • Information sharing about the results of Simon's brain injury and work in rehab
3	Family intervention	Joyce, Toby, Ed, Fiona, Simon, Kerry	• What do you remember from last time? • Drawing Simon at different phases • Asking why it happened • What is it important for Daddy to remember and how can you help him remember it? • Starting a scrapbook.
4	Behaviour management	Kerry and Simon	• Behaviour management • Parenting skills
5	Family intervention	Kerry, Simon, Ed, Toby, Fiona	• Looking at the scrapbooks • How the brain affects our feelings
6	Family intervention	Kerry, Simon, Ed, Toby, Fiona	• Family problem solving • Worries about Daddy getting ill again

The letter resulted in a helpful dialogue between the family therapy service and us, as agreed by all family members involved. It was interesting to hear the different narratives that had been presented. The issue of Simon not ringing the children had been discussed in the family therapy sessions in terms of Simon not being interested, or not a 'fit father'. Joyce reported to the family therapist that she was very keen for the children to have contact with their father, and particularly for them to keep in contact on the

telephone. She said that she had given Simon an open invitation for him to phone them at any time and for him to come round to see them. Simon's narrative around this situation, in addition to memory problems that meant he could not remember to phone, was that Jane's solicitor had written to him early on 'threatening' to take legal action if he 'hassled' and that he was contacting her too much early on in the separation. Simon also said that he did not feel comfortable ringing Joyce's house, particularly for this reason, but also when he had tried, there was no answer. It was helpful to have both these perspectives.

There was a discussion with the family therapist about Simon's particular difficulties with memory and establishing that an open invitation to ring would be difficult for him to remember and that having a written record and reminder would be helpful. The family therapist liaised with the family and a regular time was arranged for Simon to call. The children came up with the idea of drawing a picture of them, with a time and a day, to remind him to ring, and put it on the whiteboard. This resulted in some regular and consistent contact between the children and their father, enabling them to build on this relationship, and other family members to observe this working.

It became clear that near the end of the family therapy input, different family members had started to talk to each other. This indirectly resulted in Simon having regular contact with the children again. Family understanding of Simon's difficulties also returned to the agenda, particularly for the children, and another family session was subsequently arranged at the Centre.

Reassessment and review

Since a number of months had passed and the family had been engaged in other therapeutic work, there was a great deal of information to hold in mind. Therefore, a reassessment and review was appropriate. The primary therapist spoke to all the family members and the family therapist. Joyce, Simon, Kerry, Jane, Fiona, Ed and Toby were invited to the session. Jane said that she did not want to attend, but would like to be updated.

The session was a review of previous work and planning for future work, in addition to creating an environment where the children could ask questions and problem solve. The focus remained on sharing information about brain injury and rehabilitation.

Direct interventions

After the reassessment session, three further family sessions were arranged. Although these were not formal 'family therapy' sessions there were a number of similar therapeutic techniques used within these sessions.

Education

A number of devices were employed to facilitate the exploration of the meaning of ABI within the family. A particular emphasis was put on family members sharing the information they knew. These included:

- Looking at a model of the brain, taking it apart and putting it back together – the determination with which the children put this back together was striking.

- Drawing and colouring in the brain in Simon's head and showing where the brain injury was.
- Discussion about what different parts of the brain do.
- Exploring memory and emotions through play, discussion and examples.

The children put together scrap books of their pictures and the information they gathered to form an 'Information Book' (Daisley and Webster, 1999).

Circular questioning (Tomm, 1985)

This technique, where, put simply, a family member is asked to say what they think someone else in the system may be thinking or feeling, was used throughout family meetings particularly to develop a shared experience of the events that have taken place without allocating blame, to share perspectives, and find out more about the dialogue and each individual's understanding around brain injury. It enabled each of the family members to speak about what they thought was going on for another person, and then discuss that together.

These sessions were an opportunity for the children's concerns to be heard, an arena where they were encouraged to express their feelings and offered a safe space to ask questions. These are all crucial aspects of working with children whose parents have been affected by brain injury (Webster *et al.*, 2003a).

The children asked why Simon had a stroke and whether it was someone's fault, e.g. because of Simon's alcohol use. They asked why he had pins and needles before he went into hospital. In this session, the family were encouraged to discuss their understanding and their memories of this event. A shared narrative was constructed, which considered the different experiences of individuals. They also asked questions about anger and we did some experiments around recovery of the brain and experiences of frustration. They had some questions at each stage. For example, when thinking about Daddy in hospital, there were questions about the different tubes.

Experiments and metaphors

The therapists either introduced experiments or other family members suggested ideas of how to illustrate a point. We played some games to illustrate the differences between visual and verbal memory, particularly because Simon was practising using his visual memory. Kerry was particularly active and creative in thinking of ways to help the children develop an understanding of some of the elements of brain injury and to answer some of the questions they had about why their father did particular things. For example, Ed remembered that their Daddy found it difficult to get up and down the stairs, and to pick small objects off the floor when he returned from the hospital. Kerry asked the children to stand up and spin around and then try and pick up a penny from the floor, to illustrate disorientation.

Therapeutic reflection

Where possible, two therapists were involved in the family sessions. Due to service constraints it was not always possible to have the same two therapists, however, one therapist was consistent throughout the whole of the contact with the family. The reason for having another therapist was to support reflection after the session, and to observe and comment on the process during the session. This person took a similar role to an in-room consultant (Vetere and Dallos, 2005).

Reframing (Carr, 1995)

This technique was used to introduce multiple perspectives from which to think about their experiences. One example of this that Fiona gave was that Simon had given Toby some money and said he would give Ed some when he went to the shop and got some out of the cash machine. He returned without the money for Ed, who then felt upset that his brother had been favoured over him. Care was taken not to remove responsibility for aggression, nor to suggest to the children that they have any role in managing their father's aggression, but to introduce new perspectives for understanding this from our understanding of the consequences of brain injury (Vetere and Cooper, 2003). The children's perspectives were acknowledged and written down, and information about memory processes was offered.

These techniques were also used to speak about the processes that might be going on, for example Kerry explained to the children about a blood clot getting stuck in Simon's brain. Joyce said that she did not think that he was ill because of the stroke, but because of the abscess. It was reflected back that it must be confusing for the children if the adults are also confused.

Reframing was used as a tool in talking about things that were not being said. When discussing emotions and the children were drawing their feelings (particularly in relation to worry about their Daddy getting ill again) they became very involved in the drawing. Interaction with the adults decreased and they were keen to continue drawing rather than discuss the issue. Some of the adults described them as being 'naughty' and 'not listening', which was reframed as a topic that might be difficult to talk about. Fiona agreed with this perspective.

Using language and pictures to offer different perspectives

Guided by ideas used in emotion-focused family therapy (Efron, 2004), a combination of verbal and visual mediums was offered through which the children and the family system could safely express emotions. The children drew out their experiences of their father, as described in the assessment session; each child drew a different perspective of their father, and Kerry drew Simon pre-accident. They all chose different aspects of Daddy to draw. Fiona drew 'Jekyll and Hyde', which was a picture of Simon shouting. The conceptualization of abusive men as 'Jekyll and Hyde' has been used in other contexts to develop a language to speak about their experiences and observations (Bernard and Bernard, 1984; Efron, 2004). This use of language was reported to be helpful in developing a shared understanding for the problem, with some predictability (he is either Mr Jekyll or Mr Hyde) and a safe means of talking about it. Ed drew 'Daddy now'; him with a sad face. He said he was sad because he didn't see the children enough. Toby drew 'Daddy in hospital' and he drew a brain scan. The children's representations allowed discussions about the different stages of brain injury. Through drawing the pictures, it was easier for them to speak about than if they were talking directly about Simon.

Drawing different experiences of their father also opened up new conversations about their father. It seemed to provide them with a slightly different point of view and oriented them to different explanations and different feelings. When asked, they said that the differences between 'Daddy then and Daddy now' are: 'he is calmer, he shaves a lot, he sleeps in a bed, they see more of him, he forgets things sometimes (like to phone)'. This use of language was supported in therapeutic letters.

Therapeutic letters

After each session the therapist wrote a letter to summarize the main points of the previous session, and to confirm the date of the next one. In this letter the main points of the previous session were summarized and sent to all the family members involved, whether or not they had come to the session. The aim of this was to include everybody in the sharing of information, the development of the shared narrative (White and Epston, 1990) and thus began to reduce the discrepancy between stories told in the system.

Family problem solving

In the final session, the family requested that they discuss a recent incident when the children had been worried that 'Jekyll' was coming back. Simon had been decreasing his antidepressant medication gradually around the time that he had seen Jane's new partner in the car and Simon had become angry. The children said they coped with this in different ways, Fiona and Toby had run to Kerry's house, and Ed stayed close to his Daddy. The following discussion was around what to do if this happened again, and why did this happen? The children said they were all concerned that it meant that their father was becoming ill again.

The children drew pictures to describe how they know if he is 'turning into Jekyll'. Fiona said that she thought that smoking cigarettes made him like Jekyll because 'he smokes more when he is like that'. This offered Simon the opportunity to reassure the children and explain that he used cigarettes to help calm him down when he is feeling stressed. We also spoke about the effect the change in medication might have had. This session highlighted the children's concerns that smoking was going to make Simon ill again. This is why they were so keen for him to give up smoking and kept trying to persuade him to give up. Simon reassured the children that the cigarettes did not cause him to become Mr Jekyll. He commented that he didn't like it either and also finds it frightening when Mr Jekyll comes. Simon and the children decided to work together to plan what to do if it happened again.

Socializing to rehabilitation interventions

Sharing the strategies that Simon was using, and the reasons for them was an important part of these sessions (Webster *et al*., 2003a). Following information provision about brain injury and memory games, work focused on how the children could use the memory systems and contribute their ideas to helping. This linked in with the work being undertaken with Occupational Therapy (at OZC) and they developed a system; if the children wanted Simon to phone them, they put a symbol by the telephone. They began to use the whiteboard in Simon's kitchen to write down any information or activities that Simon needed to know about. They also used it to plan fun activities together. We talked to the children about using pictures instead of words when writing something down for Simon.

Parenting skills training

Individual work was conducted between one of the clinical psychologists and Simon during the period of limited contact with children. This work was structured around the Parenting Pyramid (Webster-Stratton and Hancock, 1998), which guided the clinicians to highlight alternative approaches for understanding, responding to and guiding the children's behaviour. In addition, an emphasis was placed on positive engagement, time spent with children and play, to remove the need for reactive disciplinary or behavioural strategies in response to inappropriate behaviour, and enhance positive relationships. Simon

found the pictorial and concrete mediums of this approach to be helpful compensations for his language and dysexecutive problems.

Outcome and reflection

Goal attainment

By the end of the family interventions, Simon had achieved or partially achieved all the goals related to independence and parenting (see Table 18.2). Most of the success in these goals was possible due to changes in his circumstances; initially Simon did not have the opportunity to work on these areas because he had very little contact with his children. However, once he had his own accommodation, and could see the children more regularly, he was able to work towards these goals. Information sharing throughout the system, whether it was between professionals or with family members, was a key part of these changes.

Table 18.3 summarizes changes on measures of mood and adjustment. This highlights a general reduction in anger, and increase in self-esteem. The increase in reported symptoms on the European Brain Injury Questionnaire (EBIQ; Teasdale *et al.*, 1997) can be explained by increased awareness of difficulties.

Discussion

In our work with the wider system there were a number of issues to be considered, particularly the boundaries of our service – what we were or were not able to provide to the family as a service, and being clear about what we were or were not doing in the sessions. For example, our role was in supporting information sharing between the family members and not the provision of family therapy, although some systemic family therapy techniques were used. We were often invited by family members to provide a much greater range of family services, such as family mediation. Other issues were around the delicate balancing of the needs of individuals and the complex needs of the group, particularly in the context of working with Simon individually.

It was important to be aware and respectful of the family therapy work that was happening alongside the work at the OZC. It was necessary to be clear to ourselves, the family, the rehabilitation team and the family therapy team about how this intervention was different, and what specifically we were offering that was not being offered elsewhere. We both maintained a mutual commitment to keep non-present family members alive in our respective family conversations and communicate across services as much as was possible and as much as all family members consented to such. The orientation towards brain injury education and focus on sharing information about Simon's rehabilitation was helpful in illustrating this distinction.

Consideration of all the individuals was a crucial aspect of the rehabilitation process, both in the context of extending the therapeutic milieu beyond the Centre, and in the context of engaging with wider system influences on Simon's engagement with rehabilitation. However, reflections of the therapists following sessions included containing the complexities of the family dynamics and distress, and the importance of maintaining clear boundaries of our intervention. Owing to the complexities of this work, and the need to be

Table 18.2. Summary of outcomes (goal areas)

Goal area	Outcome	Description
1. Understanding his brain injury	Partially achieved	Reported greater understanding of his injury although some inconsistent strategy application
2. Independent living skills	Achieved	Had developed and maintained effective systems for managing tasks of daily living
3. Vocation	Achieved	Now enjoys working as a window cleaner and spending time at Headway
4. Reading short stories	Partially achieved	Can read to his children when they would like him to, but this is not on a regular basis
5. Parenting	Achieved	The children and Simon plan activities together, and the children support strategy application by writing lists and using the whiteboard
6. Social interactions	Achieved	Simon reported feeling more comfortable in social situations and has new friends

Table 18.3. Summary of outcomes (questionnaires)

	At assessment	Post-rehabilitation
Anger (STAXI-II scores)	48	39
Self-esteem (Robson Self-Concept Questionnaire, Robson, 1989)	99	142
European Brain Injury Questionnaire	76	88

STAXI-II, State Trait Anger Expression Inventory – second edition (Spielberger, 1999).

even-handed in attention to different perspectives, it was important to have two therapists in the room.

The clinical psychologists involved in this work routinely valued the use of systemic ideas and methods in their practice. Through using these therapeutic skills to explore processes within the different systems, it was possible to conduct a clinically useful piece of family work. The importance of incorporating the family into the rehabilitation process has been emphasized in previous literature and is supported through this case illustration. Further, the importance of including child relatives is a crucial area of development within rehabilitation for enabling application of rehabilitation strategies into a personal context, in addition to supporting the process of emotional adjustment (Webster *et al.*, 2003b).

Conclusion

In this case, the liaison with the family therapy team was key to building bridges in the family, through sharing the 'brain injury perspective'. The work was done in parallel to Simon's rehabilitation, was largely unrelated, but had significant influences on the outcomes of his programme. It was important for the rehabilitation team to be aware of and sensitive to the other challenges Simon was facing during his programme and reasons he was not able to work towards some of his goals. This knowledge enabled the team to be more flexible with his programme and therefore more successfully support him at the appropriate times.

Within the family sessions, some key misconceptions about brain injury were highlighted. The children expressed their enthusiasm about finding out about the strategies Simon was learning and using, and through understanding them and the reasons for using them, the children were able to apply them in situations that were personally significant for them. For example, when they needed Simon to remember they had to go somewhere they would make a note on the whiteboard.

Other chapters in this book have illustrated the effectiveness of working as an interdisciplinary team. We hope that with this chapter, the importance of working with the wider system, whether it is family members, carers or other professionals, has been illustrated.

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Chapter 19

Adam: extending the therapeutic milieu into the community in the rehabilitation of a client with severe aphasia and apraxia

Jacqui Cooper and Andrew Bateman

Introduction

This chapter describes the significant gains that can still be made by clients in rehabilitation several years post-injury through thorough assessment and tailored intervention. An in-depth interdisciplinary assessment and formulation of the client's difficulties was carried out at the Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation prior to intervention that, as with Malcolm (Chapter 20) and Kate (Chapter 21), did not entail attending the OZC intensive programme. Instead, once Adam had completed the assessments in Ely, including a two-week period of work testing out specific rehabilitation approaches, two team members, an occupational therapist and clinical psychologist, provided appointments in Adam's home. The therapists provided eight individual day sessions targeting specific daily living goals through the use of errorless learning methods. We have included a description of this case to also emphasize our view that the core components of rehabilitation described in Chapter 4 can be recreated, in a less intensive way, through active involvement of family and carers in the community.

History of injury

Adam was involved in a road traffic accident in 1999. He was the driver of a car that was struck on the driver's side by another vehicle and subsequently admitted to Intensive Care. On admission, his Glasgow Coma Scale was measured at 3/15, indicating severe brain injury. A CT scan showed a left frontal haemorrhage and right-sided contusion. He had also suffered additional multiple orthopaedic injuries. He was transferred to a Neurosurgical Unit where he underwent a craniotomy and evacuation of a left frontal haematoma. Post-operatively Adam presented with right hemiplegia, dysphasia, severe cognitive deficits and post-traumatic epilepsy. He was subsequently transferred to a local Neurological Rehabilitation Unit, where he remained an in-patient from March until August 2000.

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On discharge from the rehabilitation unit, Adam was managing self-care tasks with verbal prompting and was continent. He was independently mobile and able to walk approximately half a mile with supervision (required due to apparent risk of disorientation). His post-traumatic epilepsy was reported to have stabilized with medication, but he was continuing to experience difficulty communicating due to expressive dysphasia and in completing personal care tasks due to dyspraxia.

Social history

Adam lives with his wife Alison and their two children in a privately owned house. His wife is a teacher and works approximately 40–50 hours per week during term time. Three part-time carers act as companions to Adam whilst his wife is at work to support him in completing daily living, social and leisure tasks in his community and assist him to manage his behaviour and anxiety in these situations. Prior to his injury Adam was the primary child carer, worked part-time and was also in higher education. He was a keen photographer and amateur musician, formerly playing the trumpet in a brass band.

Detailed assessment

Adam was referred by his solicitors to the OZC, where he was seen for an initial assessment in November 2002. He subsequently returned to the Centre in December 2002. A summary of assessment formulation was developed as described in previous chapters, and the diagram developed from this shared with Adam and his wife. We arranged for him to return to the Centre for an additional two weeks in April 2003. The aim of this was to provide an opportunity for us to try to determine which strategies were likely to be most effective for him to learn new skills and compensate for his difficulties in order to complete specific functional tasks. Following this we then arranged for the clinicians to work with him, his family and carers at home.

Client self-report of problems

Due to communication difficulties Adam's wife assisted him during the assessment to identify his problems. At this time they reported his main difficulties as follows:

- Restricted communication
- Fatigue
- Problem solving and processing information
- Agitation and frustration
- Dealing with unfamiliar contexts or unpredictable events
- Some memory difficulties
- Difficulties in completing tasks and following instructions (some difficulty with prepositions)
- Needing to be more independent.

Neuropsychological assessment

Adam participated in a two-week interdisciplinary detailed assessment. Testing was modified as far as possible to take into account difficulties with tasks that required complex verbal responses or choosing a response from an array. Assessments indicated that Adam

was performing at a borderline/low average range in assessment of general cognitive functioning. His results indicated memory impairments, but it was noted that he benefited from repeated presentation of material. Adam showed impairment on tests of sustained, selective and divided attention. His motor and verbal difficulties seemed to have a significant impact on his performance, especially in tasks with a timed element and on those where stimuli were presented relatively quickly. He made no errors on a test for unilateral neglect. On assessment of executive functioning he showed little planning and monitoring of behaviour, and difficulties shifting between tasks. He did show some effective use of written instructions, but this was inconsistent. Adam's performance on the Benton facial recognition test fell into the impaired range, whilst he performed in the average range on other visual spatial tasks. A screening test for dyspraxia noted particular difficulties with limb transitive actions (i.e. gestures involving pretending to use an object), perseveration, and difficulties producing hand gestures in response to spoken instructions.

Assessment of awareness, emotional adjustment and behaviour

During the detailed assessment Adam reported feeling generally happy. He indicated that at times he was understandably stressed or frustrated by the difficulties he experiences. This was reported to be a short-lived feeling lasting the duration of a task, or to last for a whole day and be accompanied by feelings of sadness, and disruption to sleep. He reported gaining positive feelings from a range of sources. Alison reported significant difficulty at times with Adam's repetitive behaviours and rigidity, for example regarding how things were placed on the dinner table. It was noted that at times, the support workers' attempts to manage such challenges led to them 'doing for' rather than supporting Adam to develop skills. Following further contact with Adam, his family and carers, a formulation of this was developed. This is presented in Figure 19.1. The aim of this was to promote a shared understanding between Adam and those in his home and community contexts. The formulation was developed collaboratively with Adam's wife Alison, who later shared this herself with Adam and his carers.

Whilst Adam appeared to have some difficulty inhibiting behavioural responses, there were no occasions of problematic, socially inappropriate or disinhibited behaviour during the two-week assessment. A memory of Adam since treasured by the team was an incident that occurred at the end of a shared client and staff Christmas meal (that took place during one of the assessment blocks), when the staff needed to gather for a team photograph. Because they all stood up at once, Adam followed and joined in the photograph, standing in the middle of the picture. This may have been interpreted as an incident of impulsivity. However, for the team, this picture became an emblem of their aspiration that clients should feel accepted as 'part of the team' even if only attending the Centre for a few days, and as a reminder to us that the client must be central to all the activities.

Assessment of language and communication

Adam's communication difficulties are complex and appeared not to be wholly related to language impairment. Dyspraxic, perseverative, dyslexic and attention difficulties were likely to have impacted on his communication skills.

Assessment of social participation changes: independent living skills

Adam's cognitive, physical and perceptual impairments significantly impacted upon his ability to carry out domestic and personal activities of daily living. Dyspraxic and

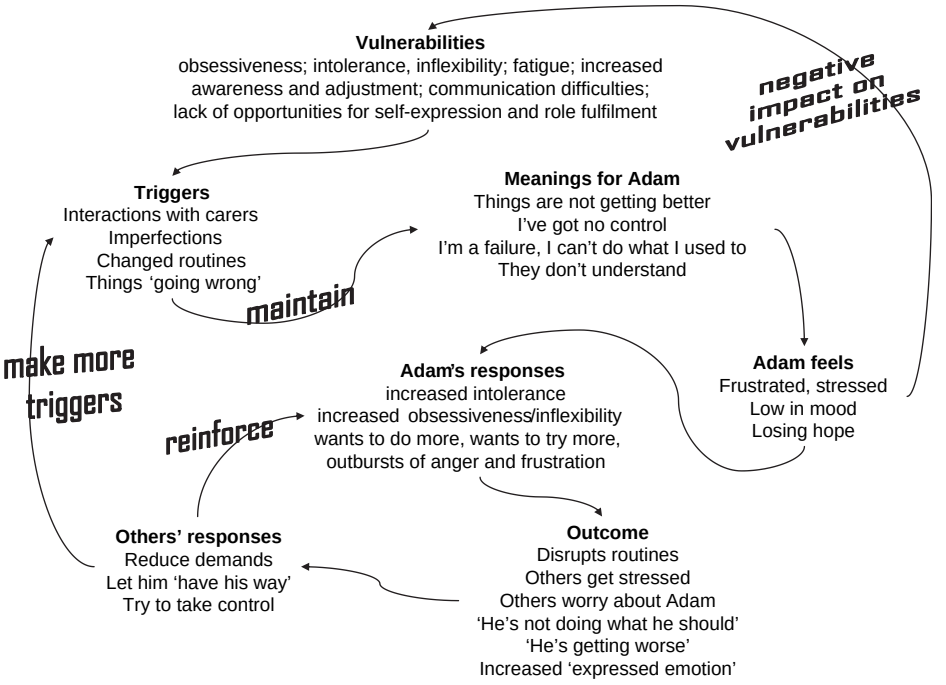

Figure 19.1. Simplified psychological formulation of factors influencing Adam's behaviour.

perseverative errors in his actions and speech are key causes of his restrictions across many activity and participation domains. As noted in the psychological formulation, responses of people at home may have contributed to ongoing restriction of opportunities for learning and independence.

Summary of assessment

At the time of assessment Adam's impairments and resulting activity and participation restrictions under the World Health Organization's (WHO, 2001) International Classification of Functioning (Wade, 2005) were:

Impairments

- Decreased range of movement in right knee
- Decreased balance mechanisms
- Significant receptive and expressive language difficulties
- Impulsivity
- Decreased attention
- Motor and verbal perseveration
- Praxis difficulties including; planning, sequencing and monitoring
- Reduced problem solving
- Post-traumatic epilepsy

Activity and participation restrictions

- Loss of employment, and unable to return to study
- Inability to carry out daily tasks independently

- Difficulty in communicating with others
- Restricted activities with his children
- Unable to drive
- Unable to participate in previous leisure activities, e.g. playing his trumpet
- Requires supervision for safety due to cognitive difficulties
- Requires assistance to manage and plan daily routine
- Dependent on Tegretol to manage epilepsy

Social and personal contextual factors

- Anxiety about engaging in specified tasks
- Frustration with performance in specified tasks
- Reduced quality of relationships (with carers) at times.

Background to choice of intervention

It was recognized that Adam presented with a complex array of difficulties and therefore it was difficult to determine exactly what progress may be made towards specific goals. However, research indicates that even patients with severe cognitive problems and apraxia can benefit from rehabilitation training of activities of daily living (Van Heugten *et al.*, 2000). Adam appeared determined and motivated to continue to progress along with the support from his wife. Due to the severity of Adam's communication and dyspraxic difficulties, it was decided that the usual intensive holistic programme run by the Centre would not be suitable, but that rehabilitation on specific goals in his home environment would be the most beneficial approach. Patients with dyspraxia are likely to manage tasks better when completed at the appropriate time of day in a familiar environment (Edmans *et al.*, 2001). Additionally, research has suggested that severity of injury and time post-injury variables should not dictate long-term rehabilitation service provision (Devitt *et al.*, 2006), endorsing our view that it was appropriate that intervention was provided to Adam.

Following a further assessment period, it was evident that Adam had difficulty learning from a 'trial and error' approach and the team concluded that an errorless learning approach should be used. There has been little published on evidence-based approaches for dyspraxia rehabilitation. However, errorless learning, a strategy originally designed for amnesic patients, is receiving growing support in this area (Goldenberg and Hagmann, 1998; Jackson, 1999). The principle of errorless learning is that the learning of new information or encoding process must occur without the patient making any errors (Wilson *et al.* 1994). Errorless learning has been found to be a successful rehabilitation technique in teaching new tasks to people with severe forms of impairment (Evans *et al.*, 2004). In order to facilitate this strategy, individuals are given the correct information during each step of learning to prevent the opportunity to make and repeat mistakes.

In a case study of vocational rehabilitation, Andrews and Gielewski (1999) illustrate the use of errorless learning with a patient with brain injury and severe amnesia. Repetition using cue cards, picture cueing and checklists allowed a woman with significant memory deficits to learn to carry out the activities of a librarian without mistakes (Andrews and Gielewski, 1999). This illustrates that even the most severely impaired individuals can learn to carry out new activities through errorless learning.

Given Adam's evident executive functioning problems, it was felt that the errorless learning approach was broadly consistent with the 'learning the steps' aspect of the goal management training described by Levine *et al.* (2000). The models of Duncan (1986) and Shallice and Burgess (1991, 1996) were helpful in thinking about the nature of Adam's executive impairment and what might be helpful in rehabilitation to support maintenance of Adam's behaviour towards the 'main goal' and related steps. Furthermore, Levine *et al.* (2000) describe successful functional rehabilitation of cooking with a woman with executive impairment, thus further supporting application of this approach.

Donkervoort *et al.* (2001) present evidence for the use of picture cueing as a strategy in apraxia from a randomized control trial. In this trial, 113 patients with left hemisphere stroke and apraxia were randomly assigned to two treatment groups. The first received strategy training, which included written or picture sequences of the activities, and the other group had standard occupational therapy. Those with strategy training showed significant improvements in activities of daily living (ADL) function at eight weeks, compared to those receiving regular occupational therapy intervention.

Taking this background evidence and Adam's full cognitive formulation of strengths and weaknesses into consideration, it was thought that a compensatory errorless approach using personally tailored photo-recipe cards may be beneficial for learning cooking skills.

Through using this approach it was predicted that Adam would relearn the recipes and they would become more implicit and automatic, at which point the photo cues could be phased out. The plan was for rehabilitation to be carried out in Adam's home environment to encourage generalization.

A study by Goldenberg and Hagmann (1998) using errorless training for patients with apraxia found that improvements were only maintained at six months in those patients that practised activities at home. Thus during and on completion of the intervention with Adam, both Alison and the support workers were informed and educated about the techniques to ensure ongoing repetition of the identified strategies.

The specific methods of intervention identified for Adam's functional rehabilitation were predominately picture cueing and repetition using an errorless learning approach. However, consistent with the core components described in Chapter 4, the intervention (tackling 'meaningful functional activity' and 'learning strategies and skills') was not delivered prescriptively or in isolation from issues such as emotional adjustment, family, social and practical environment. A shared understanding of cognitive and emotional issues was developed with Adam, Alison and Adam's carers. Adam and his wife had commented on how the milieu at the Centre had had a positive impact for Adam, how he enjoyed being at the Centre and felt understood and accepted. A further aim of our work was thus to support development of a context in which Adam felt understood and supported, where threat was reduced and the potential for good interpersonal relationships, learning and change encouraged. In this way we sought to extend the notion of the therapeutic milieu through the process of shared understanding and collaborative working.

Social participation goals and related interventions

Goal setting with the active involvement of the patient and family is well documented as being of central importance to the rehabilitation process (Wade, 2001; King and Tyerman, 2003; see Chapter 3). Therefore an initial interview was completed with Adam and his wife with whom goals were established for the rehabilitation period. The intervention was

carried out over 8 sessions of 5 hours each in his home environment and was based on the following daily living goals identified by Adam and Alison.

Adam will:

1. Walk to and from the corner shop independently whilst his support worker waits at home.
2. Use basic functions on his digital camera, to be able to take photographs of different situations and transfer them onto the computer.
3. Plan and prepare a simple evening meal for the family on a weekly basis with supervision using identified strategies.
4. Use his mobile phone to call Alison and call home independently.
5. Clean his teeth effectively using his electric toothbrush.

Goal 1: walk to and from the corner shop independently whilst his support worker waits at home

Adam identified that he wanted to be able to walk to and from the corner shop to purchase items independently whilst his support worker waits at home. An errorless technique was adopted for this task and implemented through physical repetition. On initial assessment Adam appeared confident in his knowledge about directions how to get from his home to the corner shop. He demonstrated that he was able to cross roads safely. Trials were completed with Adam walking to the shop with the therapist alongside to ensure errors were not made, the therapist progressively dropping back over later trials. The therapist did not interact with Adam when walking unless he was going to make an error in which case he was redirected before making the wrong turning. In a graded way Adam then completed this with support worker and therapist walking a block behind, which he was able to do without making any errors.

When inside the shop it was evident that he required a list of items to recall what he required. This was tried successfully and he was also able to point and use as a visual prompt to request items if unable to communicate verbally. The only area of concern was how Adam would cope and communicate should a problem arise, hence it was recommended that he should take some identification i.e. a card explaining his difficulties when commencing this unaccompanied. This goal was partially achieved in the time period and handed over to the support worker to continue to be progressed through distancing the supervision.

Goal 2: use basic functions on his digital camera, to be able to take photographs of different situations and transfer them onto the computer

Adam had recently purchased a new digital camera and was highly motivated to learn how to use its basic functions. Therefore, the second goal was for Adam to be able to use all basic functions on his digital camera and to be able to take photographs of different situations. Due to Adam's difficulties with verbal communication it was important to him to be able to communicate through photography. Being able to take photographs would also enable him to start producing his own instructions for new tasks. Simplified written instructions were prepared from the camera's instruction manual with scanned diagrams to ensure that Adam learnt how to use the camera in an errorless manner. A photo shoot was carried out in the local community to trial taking photographs of spring flowers. The therapist provided verbal, and if required, hand-over-hand direction referring Adam to

the instructions if he became flustered. He appeared to benefit from repeated errorless use of the same function to consolidate the new learning. On completing the period of intervention Adam was able to take photos using the automatic mode independently. However, he required verbal instruction on how to use the other functions with prompting to refer to the diagrams for direction. His support workers were shown how to carry this out with Adam to continue to progress his abilities with this goal.

Goal 3: plan and prepare a simple evening meal for the family on a weekly basis with supervision using identified strategies

As Adam was at home during the day he wanted to be able to prepare an evening meal for his wife and children on a weekly basis. He was able to identify some simple meals, which he wanted to learn to cook. Recipe instructions were typed up involving Adam with the steps required. To prepare the recipe cards, digital photographs were taken of the sequence and downloaded into a 'Word' document (see Appendix 19.1 for example of how this was applied to cooking 'bolognese').

Adam initially required encouragement to move from one step to the next and remain on task and to tick off each step to allow him to remember where he was up to. However, with repetition he was able to continue through the sequence of steps. At times, intervention from the therapist was required to prevent Adam from making errors and encouraging him to take a few deep breaths to control his anxiety as recommended by the psychologist. This goal was achieved and Adam now has a folder with five sets of recipe cards, to which his support workers have continued to add. He reported being pleased to be able to carry out this role again.

Goal 4: use his mobile phone to call Alison and call home independently

Adam has a mobile phone, which he and his wife identified would be beneficial if he could use in case of an emergency. Thus, the fourth goal was for Adam to be able to use his phone to call his wife and call home independently. Again, an errorless approach was applied, and this was made easier by simplifying the task and having pre-set numbers, so that just two buttons on the phone were needed. Several trials were completed to phone home when out, which were successful with minimal verbal prompting. This goal was partially achieved during the rehabilitation period, but his support workers have continued with further repetition of using the phone to ensure that Adam is able to use this in an emergency.

Goal 5: clean his teeth effectively using his electric toothbrush

Alison identified that although her husband cleaned his teeth independently, often he did not do this effectively, and so this was set as a goal area. Observing Adam brushing his teeth, it was evident that he was perseverating going over the same area without being consciously aware of this and moving on to brush other areas. Repetition and using picture cue cards with photographed steps stuck on the bathroom mirror assisted Adam to be more conscious of the steps involved in this activity. Alison reported that his performance improved so that he was managing to brush his teeth thoroughly and independently.

Summary

Adam had significant cognitive difficulties following a severe brain injury significantly limiting capacity for social participation and contributing to negative emotional responses and unhelpful interactions with carers. However, through first of all systematically assessing strengths, weakness, and emotional and contextual factors influencing performance, then sharing this with Adam and those involved in supporting him, a more accepting social context for exploring possible interventions was created. Alison supported Adam to predict his emotional reactions through sharing the psychological formulation. Support workers learned approaches to enable Adam's independence, rather than prevent self-expression and independence by 'doing for'. This could be described as replicating the initial stages aimed at on the intensive programme; supporting safety and understanding to begin to reduce discrepancies, explore new perspectives, skills and tasks in a collaborative, experimental milieu. Following further assessment of potential learning methods at the Centre, an errorless learning approach using systematic repetition, photographs, diagrams and written cues, was devised and implemented in his community. In this way, Adam made significant progress towards his identified goals. Successes and progress in re-establishing meaningful roles was thought to reciprocally support reduced sense of self-discrepancy (as expressed through Adam's reduced frustration with tasks and improved mood), in turn impacting on relationships at home. Adam continued to progress further with ongoing practice and support from his wife and support workers. Errorless learning has been demonstrated as a successful approach in people with amnesia; however, this case shows that it appears to be beneficial when working with individuals with a complex combination of cognitive difficulties including executive impairment and apraxia to ensure the correct sequence of steps is learnt when completing new tasks. Further research is required to ascertain whether errorless learning is the recommended technique for people with apraxia to learn new tasks.

The success of this case demonstrates how extension of the principles described in Chapters 1, 3 and 4 (including attention to models of cognition, learning and emotional adjustment, goal setting, the 'Y-shaped' model, and core components) was effective in bringing about change. This suggests that these principles are of value in conceptualizing largely community-based intervention for individuals whose impairments and restrictions are of such severity that they preclude engagement in the full intensive holistic rehabilitation programme. Nevertheless, the motivation of Adam, alongside the support of his wife and carers, in his ongoing rehabilitation should not be underestimated.

Appendix 19.1: Examples of some of the written instructions used for the bolognese recipe card

1. **Get out all ingredients**
   - Lean beef mince
   - Jar of pasta tomato sauce
   - 1 onion
   - Olive oil
2. **Get out all utensils**
   - Large pot or pan and lid
   - Chopping board

- Sharp knife
- Wooden spoon
- Tablespoon

3. **Peel onion**

4. **Chop onion on chopping board**

5. **Add 2 tablespoons of oil to pan**

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Chapter 20

Malcolm: coping with the effects of Balint's syndrome and topographical disorientation

Barbara A. Wilson

Acquired cognitive deficits can present themselves in many ways and can be confusing for the people affected as well as for those around them. This case illustrates the use of cognitive models for understanding an unusual neuropsychological syndrome that was not initially apparent.

Initial meeting and background

We first met Malcolm at Headway House in Cambridge in 1991. At that time his difficulty with the localization of objects was thought to be due to poor eyesight. We were starting a memory group there and wanted to administer a number of tests to the people coming to the group. One of the tests was the Raven's Standard Progressive Matrices (Raven, 1960). This test requires the person being tested to look at a matrix with a piece missing and then choose one of six or eight stimuli at the bottom of the page that will complete the matrix. Although Malcolm was articulate and had a fund of general knowledge, it was immediately obvious that he had difficulty with the Raven's test. He appeared to have problems seeing the missing part in the matrix and he could not point accurately to the stimuli at the bottom of the page. He frequently pointed to a blank part of the page or else placed his finger over two adjacent stimuli. Given that one of the major characteristics of Balint's syndrome (Balint, 1909) is an inability to localize in space (optic ataxia), we wondered if that was the explanation for Malcolm's poor pointing ability. Other characteristics include ocular apraxia (difficulty in controlling one's gaze) and simultanagnosia (problems in seeing two things simultaneously). We arranged to see him for a more detailed assessment and believed he did indeed have Balint's syndrome as we hope to show later. We continued to see Malcolm after the initial assessment to try to help with some of his problems and to try to understand the nature of his rather unusual problems.

Malcolm was 34 years old when we first met him. After a stormy adolescence, many changes of jobs and a spell in the armed services, he took an overdose of dextromoramide (Palfium) in a probable suicide attempt at the age of 24; he had been prescribed the drug for pain relief. On admission to hospital he was reported to be deeply unconscious and suffered

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repeated cardiac arrests and spinal infarcts. He was described as having gross bilateral hemisphere damage; however, there are no records of any brain scans at the time.

Although his hospital notes said there was a history of behavioural problems in childhood an EEG carried out when Malcolm was 10 years old showed no abnormalities. As a young adult, he was seen on several occasions following episodes of self-injury and substance abuse, and on one occasion was admitted following a diving accident, unconscious and suffering from hypothermia. However, there were no adverse effects reported prior to the overdose. Malcolm had played rugby, been in the army and had no known physical or cognitive disabilities.

A CT scan in 1995 revealed extensive bilateral occipito-parietal low-density lesions with involvement of both grey and white matter, extending from the level of the third ventricle to the upper parietal regions, with the left side being more severely affected. Of note was the sparing of primary visual cortex and the medial occipital lobe. These changes are characteristic of infarctions seen in the 'watershed' between posterior and middle cerebral artery territories as a result of prolonged hypotension. There was also evidence of more diffuse ischaemic damage to periventricular white matter, particularly involving the right frontal region. The temporal lobes, in contrast, appeared normal. Early attempts at rehabilitation were unsuccessful, but for three years before we met him at Headway House Malcolm had lived in his own flat in a staffed accommodation complex. He had limited mobility in a wheelchair and attended the Headway local day centre two days a week where he participated in a programme of rehabilitation and social activities.

Neuropsychological assessment

Malcolm was seen on several occasions over a period of many months. He was not easy to assess partly because he talked at great length particularly when asked to do visuo-spatial tasks; he found these difficult and may have been trying to avoid the tasks and/or show that he was not unintelligent by imparting verbal skills, general knowledge and repartee.

The main findings were as follows:

On the Wechsler Adult Intelligence Scale-Revised (WAIS-R) Malcolm's verbal IQ, 92, was at the low end of the average range with age-scaled scores ranging from a high of 12 on information to lows of 8 on digit span, vocabulary and arithmetic. This was reasonably consistent with his probable pre-morbid level of functioning as indicated by an oral version of the Spot-the-Word Test (Baddeley *et al.*, 1992). In this test pairs of words are presented, one of which is a real word and one a nonsense word. The task is to identify the real word in each case. Malcolm achieved an age-scaled score of 10 on this test, i.e. in the average range. He was unable to do any of the performance sub tests of the WAIS-R because of his inability to locate objects in space or to see more than one item at a time.

On memory tests Malcolm's immediate verbal memory span was normal with a forward digit span of 7 (and a backward digit span of 4). His immediate spatial memory span, however, was untestable as he could not even locate one block accurately and he could not point accurately to the squares in the visual short-term memory matrix (Phillips, 1983). His everyday memory as assessed by the Rivermead Behavioural Memory Test (Wilson *et al.*, 1985) was severely impaired; Malcolm's screening score was 2 (from a maximum of 12). Normal performance is at least 10/12.

Malcolm's semantic memory was apparently unimpaired. He had relatively good knowledge of word meanings as shown both by his performance on the verbal sub tests of the WAIS-R and his score on the Spot-the-Word Test. He also demonstrated good knowledge of famous personalities and was able to give sensible descriptions of what people were known for on 48 out of 50 famous names presented to him. For example, when asked 'Who is or was Dwight Eisenhower?', Malcolm said 'An American general in the Second World War. He became president after the war'.

On tests of reading Malcolm was able to read single letters, both upper and lower case, with almost 100% accuracy, making only 2 errors to 208 presentations of single lower case or upper case letters at sizes of 2mm, 4.5mm, 6mm and 7mm (the errors were to the lower case 'o' at 4.5mm, and the upper case 'J' at 6mm). However, despite this good reading of single letters, even when these were only 2mm in height, Malcolm had difficulties with single word reading and spelling, was unable to read sentences and was unable to write.

Malcolm's visuo-spatial abilities were severely compromised. As noted above, he was unable to complete any of the performance tests on the WAIS-R. Other areas of difficulty included problems with spatial imagery, picture scanning, picture matching and visual immediate memory. Spatial imagery was assessed with the manikin test (Ratcliff, 1979). Pictures are shown of a manikin holding a black circle in one hand, sometimes the manikin is facing forward, sometimes backwards, sometimes upside down facing forwards and sometimes upside down facing backwards. The task is to say or indicate which hand the black circle is in. Malcolm was at chance on this mental rotation test. On the picture scanning task of the Behavioural Inattention Test (Wilson *et al.*, 1988), Malcolm scored only 2/9 (severely impaired). Picture matching was assessed with the forced choice version of the Benton Visual Retention Test (Benton *et al.*, 1983). This test involves matching a reference pattern to one of four possible choices that vary both in their constituent elements and the relative positions of these elements. Malcolm's visual short-term memory (VSTM) was severely defective, as he only scored 3/24 on the test devised by Phillips (1983); this task requires remembering the pattern of positions of filled squares in a 4×4 matrix. Of course, this may have been a consequence of his localization skills rather than a pure VSTM deficit.

Malcolm was also assessed with the Visual Object and Space Perception Battery (VOSP; Warrington and James, 1991). The VOSP contains four spatial subtests. In the Dot Counting subtest, subjects are asked to count groups of five to nine randomly positioned dots. For the Position Discrimination subtest, there are two horizontally adjacent squares, one with a dot positioned exactly in the centre, one with a dot slightly off-centre; the task requires deciding which dot is closest to the exact centre of its respective square. For the Number Location subtest, two vertically positioned squares are used, there is a dot in the lower square, and the upper square contains a number of response digits, one of which corresponds exactly to the location of the dot in the lower square; the subject's task is to report this digit. For the Cube Analysis subtest, the number of cubes in drawings of small stacks of cubes must be counted; the test stimuli are graded in difficulty by increasing the number of cubes from three up to ten and by including 'hidden' bricks that must be deduced to lie behind those immediately visible.

Malcolm passed the VOSP's shape detection screening test, which requires detecting the presence of a fragmented letter 'X' against a noisy visual background, and is taken by Warrington and James (1991) to indicate that there is no gross deficit of visual sensory

processing. However, a different pattern emerged with the four space perception subtests; Malcolm failed all of them, with exceptionally low scores. He was effectively performing at chance level.

Visuo-motor problems were also evident. Malcolm's performance on Corsi blocks was strikingly poor, to the extent that he was unable to touch a single block indicated by the tester (span 0). However, when asked to touch parts of his body, he could do this without error. Although not entirely normal, Malcolm's body-directed movements were much more fluent than his movements when performing the Corsi blocks task, showing that his problems with this task did not simply reflect defective motor control.

Malcolm's gross eye movements, for example when requested to direct his gaze to different corners of the room, appeared to be normal. However, detailed tests of eye movement revealed major difficulties. An attempt to record eye movements to complex visual displays had to be abandoned when Malcolm proved unable to carry out the calibration routine of scanning a 3×3 matrix of locations in a fixed (top left to bottom right) order. Records of saccades to simple targets showed that Malcolm found it almost impossible to maintain accurate central fixation during the 1500 ms before target presentation.

After the assessment

We went on to compare Malcolm with another man of the same age who had survived herpes simplex encephalitis. Both men had sustained their brain damage at the same age and both had developed reading problems. In other ways, however, they were very different. Malcolm knew **what** things were but not **where** in space they were. The other man had no problems locating objects, he knew **where** they were but not **what** these objects were. We reported this in a paper called "Knowing where and knowing what: a double dissociation" (Wilson *et al.*, 1997).

One question that we asked ourselves was whether Malcolm really had Balint's syndrome. We believe he does indeed have this disorder as the pattern of his results rules out poor eyesight or visual agnosia as explanations of his difficulties (his ability to recognize visually presented objects was good). It is true that his reading was poor, but this might well reflect the severe problems in the spatial control of eye movements noted when we attempted formally to record them. Similarly, his ability to scan pictures systematically was defective, even though he could identify items in the scene. Neither did Malcolm seem to have a straightforward motor disorder; he was able to touch parts of his body without difficulty. It was visually directed movements to external space that caused him particular problems. Given that we can rule out these other causes for his problems what characteristics does he show to support the diagnosis of Balint's syndrome? He shows deficits in directing gaze, a limited field of attention when describing complex scenes, and impairment of some object-directed movements of the hand performed under visual guidance, while movements that do not require visual guidance, such as those directed to the body, are executed correctly. A classic paper of the early twentieth century in addition to the case reported by Balint (1909) was that of Holmes (1918) and indeed the disorder exhibited by people like Malcolm is sometimes called Balint–Holmes syndrome. Balint (1909) emphasized the visuo-motor and attentional aspects of the disorder while Holmes (1918) emphasized the visuo-spatial rather than visuo-motor aspects of the disorder because the same errors were made with movement or with verbal

report. For example, Holmes described a case where a brain injured soldier could only pick up a matchbox from his locker after repeated gropings, Holmes (1918) noted that the soldier found it just as difficult to report verbally the locations of objects, and even their relative positions. Malcolm showed the same pattern of behaviour. Although Malcolm was very poor at visuo-motor tasks, such as the Corsi blocks, his spatial deficits were equally evident when a purely verbal report was required, as in the VOSP subtests (Warrington and James, 1991). For a good and thorough review of Balint's syndrome see Rizzo and Vecera (2002).

Therapeutic interventions for Malcolm

We wish to make it clear from the outset that we have failed to improve Malcolm's basic difficulties in localization despite many attempts at treatment and we describe some of these below. We have found it possible to help him compensate, in part, for these problems and we have been able to provide ongoing support for Malcolm. He likes visits from neuropsychologists and discusses his numerous physical and social needs. Together with clinical psychology trainees we have become involved in sorting out Malcolm's physical needs (his wheelchair), his housing needs and his care needs, and seem to be one of the few constant sources of support in his life. Psychologists do not typically engage in such tasks but in this particular case we have chosen to do so because of the therapeutic relationship built up between Malcolm and our department over the years. One of the earliest sources of help we were able to offer was the provision of an explanation for Malcolm's difficulties. He was considered to have poor eyesight and we were given this information when we first saw him. People assumed that he did not reach for things accurately because he could not see. Similarly, his problem with reading was thought to be due to problems with visual acuity. We showed this was not the case and that his problems were due to other deficits. Malcolm, himself, appreciated having a name to give his disorder. He tells people he has Balint's syndrome and that papers have been written about him. Each time new carers are involved in Malcolm's care the information has to be provided anew. We provide a summary of the latest information supplied to his carers.

To whom it may concern

Malcolm sustained anoxic brain damage in 1981. This left him with both physical and cognitive problems. The cognitive problems are unusual and not always easy to understand. Malcolm has a rare syndrome known as 'Balint's syndrome'. The main characteristic of this syndrome is difficulty locating things in space. Malcolm can **see** things perfectly well but he has difficulty in reaching for them accurately so tends to fumble around when trying to locate his wheelchair control or the remote control on the TV. He does get there in the end but it is harder for him than for other people. This means he is likely to have more accidents such as spilling coffee or knocking over the telephone. Because Malcolm has poor knowledge of his own position in space he is likely to position himself at an odd angle in his wheelchair or his bed. Another problem Malcolm has is difficulty processing two objects or letters that are side by side. He will only attend to one of them (this is known as simultanagnosia) and this is why he has problems with reading; he cannot 'see' or 'attend to' more than one letter at any glance. In addition, Malcolm is disoriented in space – he finds it difficult to know where places are in relation to himself.

For example, he recognizes places in Cambridge but has great difficulty telling you how to get from one place to another. In his own flat, he can more or less point to where things are if his eyes are open but when his eyes are closed he usually points to the wrong place if asked 'where is the bathroom/kitchen' etc. Verbally, Malcolm is very good and he has a wide general knowledge. His apparent clumsiness and awkwardness are not due to lack of effort – or because he can't be bothered. He really has major problems with visuo-spatial tasks.

Like Kate in Chapter 21, providing information for carers is a simple, inexpensive but often helpful strategy.

Attempts to improve Malcolm's ability to localize objects

The first attempt to improve Malcolm's localization skills took place in 1995 and was carried out by Robyn Tate from Sydney during her six-month sabbatical at our unit in Cambridge. The training task was based on 2.8 by 2.8 centimetre squares drawn on white paper (i.e. the length and width of the Corsi blocks used in the assessment). In the baseline, we used (1) single squares, (2) three squares on a page and (3) nine squares on a page. The squares were randomly aligned. Malcolm was given a pen and asked to put a mark inside the square(s). When single squares were shown to him he managed to put a mark inside the square on six of seven occasions. When there were three squares on the page he was able to put a mark in two of the three and when nine squares were presented he was able to mark correctly six of the nine. It was also noted that Malcolm was unable to reach for auditory targets (he failed all of the six targets presented). We felt that increasing the number of alternative targets led to greater difficulty in successful localization so decided to gradually increase the number of alternatives in the hope that this would lead to improved performance. We also wanted to know whether any improvement on localizing the squares would generalize to other similar tasks such as the number localization task from the VOSP and more distant tasks such as typing on the computer and reading. We also predicted that there would be no improvement on unrelated tasks such as a memory task. Consequently, we administered six tasks namely the Squares (the training task), Corsi blocks, Number Location from the VOSP, Words from the Schonell Graded Word Reading Test (Schonell and Schonell, 1963); typing two words on the computer and an auditory verbal learning test.

In the training period Malcolm was seen for 45 minutes for nine sessions and first taught a mnemonic to help him to attend to what he was doing. This was GRASP FIRM which stood for Get Ready, Attend, Fixate, Scan and Move. Malcolm learned this with little difficulty. In the second step, his hand was guided to the square by the psychologist, step three involved Malcolm guiding the psychologist's hand (but this was not allowed to stray from the target) and in step four the psychologist's finger was placed in the square and Malcolm was required to move his finger towards this. Disappointingly, the results showed no significant difference in any of the tasks from baseline to the end of treatment. We felt that the task of localizing a position in space is normally automatic, we don't have to think about it, whereas we had tried to bring localization under Malcolm's voluntary control and maybe this is why we failed.

In the second attempt to help improve his localization we wanted to see whether automatic responses were better than intentional responses. The psychologist first pointed to the square and then asked Malcolm to do so as soon as he was ready. Again no

improvements occurred. What was clear however was that Malcolm was always better with one square than with several. If more than one square was present he frequently complained about double vision and said things were better if he closed one eye. We then systematically tested him on the squares and the Corsi blocks under four conditions: right eye covered, left eye covered, no eyes covered and both eyes covered. He seemed to be better with his left eye covered as his average here over several trials was to touch accurately 3 blocks from the 9 tested on each trial. In each of the other conditions his score averaged 1/9 correct on each trial. We next investigated whether there was a difference between pointing and grasping. We arranged nine different everyday objects on his wheelchair tray (e.g. salt cellar, pencil, comb) and asked him to point to a named object. This he could do without error. We then asked him to pick up a named object. Apart from a slight awkwardness he could do this accurately so there would appear to be no difference between his ability to point to objects and his ability to grasp objects (as is sometimes seen in people with unilateral neglect (Harvey, 2001). Malcolm could also point accurately to different parts of his body such as the lower most part of his right ear, the tip of his left thumb and the inside corner of his right eye.

Thus we found that Malcolm could cope with objects if they were different from each other even when there was an array of nine presented together. We then put nine spoons on his tray, eight were dessert spoons and one was a soup spoon. He could accurately locate the soup spoon and could grasp the handle which sometimes faced him and was sometimes pointing away from him. Furthermore he did this with very little fumbling. When asked to select a spoon (pointed to by one of us) from an array of identical spoons, however, he frequently selected the wrong spoon.

The next step was to see whether we could improve Malcolm's performance on the Corsi blocks by marking them in some way. If we numbered the blocks one to nine and asked Malcolm to point to the number six (or whatever), he improved his performance by over 90%. We then placed small objects on the blocks (a different object on each block). The tester pointed to the object first and then asked Malcolm to find the object. In 1999 he averaged 5/9 correct on each trial but by 2000 he could do this task and typically scored 100% correct with this task under the four conditions. On a later occasion we tried sticking different coloured paper on to the blocks and this, too, improved his performance. Thus it was not that Malcolm could not localize objects in space, it was that he could not spatially discriminate between objects if these were similar. This could have been due to his simultanagnosia. If he was only able to attend one object at a time then presenting two or more similar objects could have been distracting whereas ensuring an array was dissimilar could have reduced this distraction. It was also the case that these improvements worked best when Malcolm was not tired. After several trials his performance typically deteriorated.

In short we were unable to improve Malcolm's ability to localize from an array of identical or very similar objects but we could help him compensate for this by (1) presenting only one object at a time or (2) making the array of objects dissimilar to one another or (3) marking the similar objects with numbers to distinguish them.

Investigations of Malcolm's topographical knowledge

We suspected that the problem Malcolm had with spatial localization would extend to more general problems with the environment so that he might have difficulty knowing

where he was in space. Thus we began investigating his topographical knowledge. We asked him about the towns and cities he knew in the United Kingdom and he listed 11. We then showed him a blank map of the United Kingdom and asked him to point to the 11 towns on the map. Apart from Cambridge, which was close to the right map location, Malcolm was very poor. Of course, this could have been because he cannot point accurately and it is possible that he had a good internal knowledge of the location of these places. With Professor Andrew Young and a number of trainee clinical psychologists we began a detailed investigation of Malcolm's topographical knowledge (Wilson *et al.*, 2005).

Although problems in finding one's way about are often called 'topographical disorientation', there can be different types of topographical disorientation and several underlying causes for this. In 1999 Aguirre and D'Esposito suggested there were four kinds of topographical disorders: landmark agnosia; egocentric disorientation; heading disorientation and anterograde disorientation. They believe that in order to find our way about we need to be able to recognize familiar buildings and landmarks in the environment, represent our (egocentric) position with respect to any present landmark, use more abstract (exocentric) representations to create an idea of the particular direction to follow in order to get to a particular goal, and learn and update information in response to new or changed environments. Impairment of each of these abilities leads respectively to landmark agnosia, egocentric disorientation, heading disorientation and anterograde disorientation.

In landmark agnosia the main deficit is an inability to recognize prominent, meaningful environmental features, so landmarks cannot be used for the purposes of orientation. These are among the best studied cases of topographical disorientation and provide evidence that a cortical region in the area of the lingual and fusiform gyri is involved in landmark recognition.

Patients with egocentric disorientation have bilateral or right parietal lobe damage and have been traditionally labelled as having topographical disorientation. Deficits are not strictly confined to the topographical sphere but are seen on a wide variety of visuo-spatial paradigms, including mental rotation and spatial span tasks (Aguirre and D'Esposito, 1999).

People with heading disorientation recognize landmarks but cannot derive directional information from these landmarks. They appear to have lost a sense of exocentric direction or 'heading' within their environment. Very few of these patients have been described and observations are regarded as tentative. The anatomical area involved is believed to be the right posterior cingulate region.

The last of Aguirre and D'Esposito's types of disorientation is anterograde disorientation. In the three types described so far, patients have problems with both novel and familiar environments. In this fourth type, however, are patients whose problems are primarily to do with novel environments. Environments known for at least six months before their lesions should cause no difficulties. The area responsible appears to be the parahippocampal region.

We believe that Malcolm has egocentric disorientation. As Aguirre and D'Esposito suggest this is not just a problem with finding one's way around but results from a more general failure to code positions in body-centred co-ordinates. Thus egocentric disorientation will always be linked to deficits in a wide range of visuo-spatial tasks. A few patients with this disorder have been described. Five are described in the Aguirre and D'Esposito paper.

The first was a soldier injured by a machine gun bullet that entered his head on the right side and exited on the left. The main area of damage appeared to be in or around the

neighbourhood of the angular gyrus (Holmes and Horrax, 1919). He was unable to orientate accurately towards objects that he perceived and recognized. He frequently bumped into objects when walking despite seeing the objects. He had difficulty perceiving more than one object at a time. His reading was impaired because he could not read words in the correct order. Although able to write, his writing was almost indecipherable because he placed the words irregularly on a page and sometimes one word crossed over another. He was unable to recall topographical memories acquired in the past and could not learn his way in new surroundings.

In 1977 Kase *et al.* described a 63-year-old woman who was found, on post-mortem examination, to have bilateral infarctions of the superior parietal lobules. When examined before her death, she was unable to localize objects in space using vision, and was also unable to localize properly to sound (unlike Holmes and Horrax's patient). She was unable to write but could read individual words and short sentences. She could not find her way around the hospital, could not locate her bed in a six-bedded ward and found it very difficult to lie in bed in the correct orientation. On attempting to do this she might lie across the bed or try several approaches including an upside-down approach. She found it difficult to sit correctly in a chair. She lost her way in the street and, again like the soldier described by Holmes and Horrax, bumped into objects that she was able to see and recognize.

Levine *et al.* (1985) describe a 43-year-old man with visual disorientation following bilateral parietal lesions. Despite no problem identifying objects, he could not tell which of two objects was nearer to him, he could not reach accurately for objects and he collided with objects when walking. He had difficulty tracking moving objects and fixating on stationary ones. He could read a few isolated words in a paragraph but in random order. He was frequently lost in his own house, could not cross the street because he could not judge the speed and distance of traffic and could not describe how to get from his house to the corner grocery store. He had made this trip several times a week for five years. He could, however, describe the store and the proprietor.

Two other patients are reported by Aguirre and D'Esposito, one of whom could not do the Manikin test (Ratcliff, 1979) and one of whom could not do Corsi blocks. Both these tests had been given to Malcolm whose performance was exceptionally poor.

All five then could recognize and name objects, all had difficulty finding objects in space and/or judging spatial relationships. Most had problems with reading although some could read single words and short sentences. Reading words in order appeared to be the major difficulty. Writing problems were also reported. Four of the five patients had bilateral parietal or occipital-parietal damage and for one (Hanley and Davies, 1995) there is no reported area of damage. Aguirre and D'Esposito also point out that although visual recognition was reported as relatively well-preserved, none of these patients have been tested specifically on visual recognition tasks employing 'landmark' stimuli. These patients (or some of them) may well have had Balint's syndrome and it has been reported that people with Balint's syndrome have difficulty finding their way around. We have already argued that Malcolm has Balint's syndrome. Is it possible that all people with egocentric disorientation have this?

Does Malcolm have egocentric disorientation?

Malcolm shares many of the characteristics seen in the five patients described in the Aguirre and D'Esposito paper. He (1) has bilateral parietal lobe damage, (2) can recognize and name objects, (3) has poor spatial imagery, being at chance on the manikin

test (Ratcliff, 1979), (4) has problems reading and writing, (5) cannot reach accurately and (6) is particularly impaired on the Corsi blocks test. So Malcolm's visuo-spatial problems are similar to those noted in other cases of egocentric disorientation, but what about his topographical abilities?

Because he is in a wheelchair and needs help for many tasks including toileting, dressing and bathing, and because he never goes out alone, we cannot say for sure that Malcolm gets lost within or outside his house. What is clear, however, is that he cannot describe routes, even those he travels regularly. He cannot tell someone how to get to the day centre he attended twice a week for several years (he was taken by a specially adapted car), or to the college where he attends a special education class. In attempting to describe a route he provides little or no detail on distances or directions. He is, however, able to describe landmarks.

Malcolm is usually able to locate places in his own flat. For example, when asked to point to the bedroom with his eyes open he points in the right direction. When his eyes are closed, however, he is spectacularly poor. So when asked to point to the washing-machine, fridge, computer, etc., he sometimes points to the wrong side of the room and has never pointed along a trajectory passing within 3 feet of the object.

We went on to test Malcolm with a famous landmark recognition test devised by McCarthy *et al.* (1996). He scored 16/25 correct when asked to name each famous building or landmark. The mean score of a group of 10 age-matched controls was 15.2 (range 13–16; SD 1.14), showing that Malcolm's performance was unimpaired. On another occasion a week or so later, we asked him to provide from memory information about each landmark; he was correct on 23/25 occasions, showing intact semantic knowledge of famous landmarks. For example, to the question 'What are The Pyramids and where are they?', he replied that they were built by The Pharoahs as tombs for individual pharoahs – like a mausoleum. They are in Egypt.

The Cambridge Landmarks Tests

In an attempt to further understand Malcolm's topographical problems we constructed a set of tests intended to probe abilities identified as important by Aguirre and D'Esposito (1999). These tests were all based on a common set of locations in Cambridge, where Malcolm has spent a large part of his life.

We took photographs from 4 different viewpoints of each of 20 buildings and landmarks in Cambridge which Malcolm said he knew. These 80 photographs were presented for identification to 12 people who had lived in Cambridge for more than 2 years. We then looked at the 12 landmarks with the highest recognition scores among the 12 control subjects. These 12 locations were used to construct 2 photograph-based and 2 purely verbally administered tests of topographical abilities. The tests were given to Malcolm and to five age-matched controls, all of whom had lived in Cambridge for at least three years and felt they knew Cambridge well.

Test 1: landmark recognition

On the assumption that landmark recognition should not be impaired in people with egocentric disorientation, we showed one photograph of each of the 12 locations to Malcolm and to the 5 control participants. These were shown one at a time, in a fixed pseudo-random order, leading to a score from 0 to 12 for the number of locations correctly

identified. We accepted identifying information (e.g. 'the church on the corner of Hills Road') if the correct name was not known.

Test 2: orientation in an egocentric co-ordinate frame

This test used two different photographs of three locations. On any one trial, a photograph was presented, with no identifying information or indication of the whereabouts of the location. Participants were then asked "If facing the building shown in this photo, do you turn left or right to get to X?", where X was another location from the full set of 12 locations. Each of the 6 photographs was used twice, each time with a different destination location for the question, so that the correct answer would be 'left' on 50% of trials and 'right' on 50% of trials. The resulting 12 trials were given in a fixed pseudo-random order, leading to a score from 0 to 12 correct choices of direction (chance = 6/12 correct). We predicted that if Malcolm had egocentric disorientation he would find this difficult as he had to know where each of the two locations were in relation to himself (an egocentric task).

Test 3: use of an exocentric representation

This test was based on the names of the locations and did not use photographs. On each of 12 trials, the participant was asked which of 2 possible locations was nearer to a target location (for example, 'Which is nearer to the Fitzwilliam Museum, Old Addenbrooke's Hospital or Guildhall Square?'). The 12 locations known to Cambridge residents were used once each as targets, in a fixed pseudo-random order, leading to a score from 0 to 12 for the number of correct answers (chance = 6/12 correct). We predicted that Malcolm would be able to do this task as it involves exocentric representations.

Test 4: route knowledge

This was our second verbal task. We asked for a description of the route between six pairs of locations (e.g. 'How do you get from Browns to the Fire Station?'). The 12 locations were used once each to create the 6 pairs used in the test.

To score the answers from this test, Malcolm's responses and responses of the five controls to the six route knowledge questions were written down verbatim and given blind to three local people who were asked to rate the six responses to each question from best (ranked 5) to worst (ranked 0). Thus there was a maximum score of 30 (the sum of the 0–5 rankings for each of the 6 questions) from each rater. We predicted that Malcolm would find this difficult as it involves both exocentric and egocentric representations according to Aguirre and D'Esposito.

Test results

Thus we gave Malcolm four tasks of which we expected him to show normal performance on two that were exocentric tasks and impaired performance on two that were egocentric tasks. To ensure that participants were not helped or cued from one task to another, especially for the recognition of the photographs, we ran the tests in a fixed order, with test 1 first, test 2 second, test 3 third and test 4 fourth. Our predictions were all fulfilled as Malcolm scored 12/12 on the landmark recognition as did the 5 control participants. He

scored 2/12 on the test of egocentric orientation with the control participants scores ranging from 11 to 12 correct. On the exocentric orientation task, Malcolm scored 12/12 with the control participants' range 11–12. In the route knowledge task, all three of the blind raters ranked Malcolm's answers 0/30. An example of one of his responses comes from the question 'How do you get from the Roman Catholic Church to Old Addenbrooke's Hospital?'. Malcolm said 'turn back on yourself and go towards… (long pause). I know where it is but I can't really describe it.' One of the control participants' responses was 'Turn left onto Hills Road. Turn left at the cross roads onto Lensfield Road. Go to the end of Lensfield Road. Turn right at the mini-roundabout and Old Addenbrooke's is about 150 metres down on the right-hand side.' In order to make sure that Malcolm's poor performance was not simply due to the fact that he never went out alone, we gave the four tasks to Kate (see Chapter 21) as she never went out alone and was confined to a wheelchair. Kate's performance was indistinguishable from the healthy control participants.

Conclusions

Although, we have known Malcolm for a long time, in many ways we have made very little difference to his life. He remains very disabled and dependent on others for his care. We have, perhaps, made three contributions to his wellbeing. One has been to explain to him and his carers the nature of his problems and why they occur. In particular we have been able to address some of the misunderstandings, for example that he has poor eyesight or is deliberately being awkward. One of his helpers, for example, thought that larger keys on the computer keyboard would help Malcolm. We explained that this would not help his inability to see two things simultaneously and that it would be better to make the keys as different as possible from one another perhaps by making them different colours.

The second contribution has been to find a few ways to compensate for his simultanagnosia and poor spatial abilities. This has been achieved by making stimuli in any array more discriminable, i.e. using different numbers or colours on top of the similar objects. We have not been able to help Malcolm position himself more accurately in space and he sits in his wheelchair and lies in his bed in strange and awkward positions. We feel this needs to be managed through a better wheelchair and bed and his local services are trying to arrange this but progress here is very slow.

The third contribution we have made and this has not been well documented is in the provision of emotional support for Malcolm over the years. For almost 14 years he has had regular visits from clinical psychologists and clinical psychologists in training. At various times Malcolm has brought up problems he is concerned with. When we tried to address these he backed off and said he was no longer concerned or that he had forgotten what he said before. Our feeling is that he was afraid of being abandoned and of losing the (albeit restricted) degree of independence he had. It would appear that he brought up problems when he felt most vulnerable, for example when one trainee psychologist was leaving and another was taking over. Once reassured that psychological support would continue he calmed down. The main support was to be there to let Malcolm talk about his concerns and worries and to act as intermediaries between the various agencies involved in his care. Although some might argue that this is not the responsibility of psychologists, in this

particular case, we have been the ones in contact for the longest period of time and provided continuity so feel it would be unfair on Malcolm to abandon him now.

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Chapter 21

Kate: cognitive recovery and emotional adjustment in a young woman who was unresponsive for several months

Barbara A. Wilson

This chapter describes a young woman who was reported to be in a vegetative state for several months. She made a good cognitive recovery despite severe physical impairments but needed long-term support for emotional adjustment. This case illustrates how developing a shared understanding of Kate's strengths and difficulties with her and those around her was an important step toward re-establishing her sense of social identity. This, in turn, led to increased social participation.

Background and illness

Kate was born in 1970. She was the second daughter of a professional family living in Cambridge. She had a happy normal childhood with no serious illnesses. Her older sister trained as a medical doctor and Kate went to university to study history. After completing her degree Kate trained as a primary school teacher but because she felt her spelling was poor she chose to work at a nursery school near Peterborough. She was living with her boyfriend whom she hoped to marry and they planned to have several children. At the age of 26 years Kate developed a sore throat and a headache. Her mother described what happened.

> One Sunday Kate phoned to say she had a sore throat. On Monday she went to work. I phoned on Tuesday but didn't speak to Kate, I spoke to Kate's boyfriend. He said Kate was not well and was in bed. He went to work on Wednesday and when he came home he could not wake her. He telephoned an ambulance and Kate was taken to hospital where she was said to be in a coma. They didn't know what was wrong. The next day Dr Allen came from Addenbrooke's and said Kate had to go straight there. He had arranged the ambulance. I was relieved as he was a neighbour of ours so was known to us. She went to Addenbrooke's where it was difficult for them to diagnose her condition but she was found to have an acute disseminated encephalomyelopathy. Dr Allen said that although they knew it was encephalitis they could not identify the particular virus. He also said that Kate's immune system had not switched off so we took that to mean that Kate had damage from the encephalitis together with damage from the immune system attacking the brain stem.

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A CT scan at the time showed diffuse cerebral swelling with a large ventroponto medullary (brainstem) lesion and lesions in both thalami. A magnetic resonance imaging (MRI) scan confirmed this. Kate was found to have widespread hyperintensity in the brain stem, both thalami and both medial temporal lobes. She was recruited to take part in a positron emission tomography (PET) study in an attempt to assess any residual cognitive functioning in people who are in a vegetative state (Menon *et al.*, 1998; Owen *et al.*, 2002). Before discussing the results of the PET scan we will discuss the definitions of coma, the vegetative state and minimal consciousness as these are the three conditions seen in patients with severely reduced states of awareness and they are not easy to distinguish.

Coma is a sleep-like state in which the eyes are continuously closed, there is an absence both of purposeful movement and of sleep–wake cycles and there is no evidence of self-awareness. The comatose individual is not able to obey commands or to speak, and cannot be awakened. There may also be depressed respiratory function. The Glasgow Coma Scale (GCS; Teasdale and Jennett, 1974) is the tool most commonly used to measure brain injury severity. Scores range from 3 to 15 depending on the stimulus required to induce (1) eye-opening, (2) the best motor response and (3) the best verbal response. A GCS score of 8 or less that persists for at least 6 hours is considered to reflect a severe head injury and a GCS of 8 or less that persists for 24 hours is considered to be a very severe head injury. Coma can, of course, follow non-traumatic causes, for example respiratory failure, or encephalitis as was the case with Kate.

Patients who experience severe brain damage may be left permanently unaware or in a persistent vegetative state (PVS). Common causes of PVS include head injury and hypoxic insults to the brain. Criteria for diagnosing PVS have been generated by a number of groups but these criteria are not always useful in practice. Diagnosing PVS is of particular significance because once a diagnosis has been made active medical treatment can be stopped. A diagnosis of PVS depends on providing evidence to demonstrate a lack of awareness. There are clear problems in assessing an individual's level of awareness and, therefore, in diagnosing PVS (Shiel *et al.*, 2004). According to Shiel (2003) once a person in coma has opened his/her eyes (and even in severe cases this almost always happens by the fourth week) we can no longer say they are comatose. Coma evolves into the vegetative state (VS), minimal consciousness, consciousness or death. People in the VS have no awareness, do not feel pain, have no purposeful movement but they do have sleep–wake cycles and may have normal respiratory function. People in the minimally conscious state (MCS) have limited self-awareness and do feel pain. They also have sleep–wake cycles and may have some limited capacity for movement. Although eye-opening is the key factor for deciding whether someone is or is not in coma, it is more difficult to distinguish between the VS and the MCS. The main difference is the limited self-awareness shown by those in the MCS. The distinction is important, however, at least in the UK, as decisions to withdraw feeding and hydration are based on this. Courts may agree to the removal of food and water in someone who is vegetative but not in someone who is minimally conscious. Because of this people have tried to provide objective criteria for distinguishing between the two. The Royal College of Physicians (see Bates, 2005) provides guidelines that are accepted in the UK. In the USA Giacino and Kalmar (1997) say that 'Conceptually, the defining difference between VS and MCS is the complete absence of awareness in the former and its partial preservation in the latter' (p. 37). They go on to say, however, that it is not easy to distinguish between the two conditions and some investigators believe that clear boundaries do not exist between the two. They say that one or more of the following behaviours should be present before a diagnosis of MCS can be made:

- Following simple commands
- Manipulation of objects
- Gestural or verbal 'yes/no' responses
- Intelligible verbalization or
- Stereotyped movements (e.g. blinking or smiling) that occur in a meaningful relationship to the eliciting stimulus and are not attributable to reflexive activity.

Other responses that can be observed in the borderline zone between VS and MCS include visual tracking, crying, smiling and non-stereotyped motor responses. The same two authors have recently provided guidelines for the differential diagnosis between the two conditions (Giacino and Kalmar, 2005)

Two papers report on the problems of misdiagnosis of the VS. Childs *et al.* (1993) and Andrews *et al.* (1996) say that 37% and 40% respectively of people described as being vegetative were misdiagnosed. Thus, it can be seen that misdiagnosis is common, so that although Kate, the subject of this chapter, was described as being vegetative in the PET study (Menon *et al.*, 1998; Owen *et al.*, 2002), it is possible that she was in fact minimally conscious at the time. At best, however, she was not responding to commands, she showed no consistent spontaneous or elicited motor responses or eye movements and she was not able to communicate. She had a sleep–wake cycle, however, and anecdotal evidence suggested that she occasionally followed family members with her eyes. Although no formal assessments were carried out, a psychologist and a medical intensive care specialist spent between 2 and 3 hours observing Kate prior to the PET scan. They tried to elicit responses through loud clapping and other stimuli. Kate herself says she became aware in October 1997, i.e. some four and a half months after the onset of the illness. It is possible that by then she had made the transition from the VS to the MCS.

Owen *et al.* (2002) describe the visual stimulation procedure used for the PET scan. Ten photographs were obtained from Kate's family and from the partner of an age-matched control (the control had to be a man as it is not acceptable to scan women of child-bearing age for research purposes). Neither Kate nor the control subject were aware of which photographs had been provided. The photographs included family members, pets and the subjects themselves. These were digitized and presented in a large format against a black background on a high-resolution monitor. The monitor was placed at a comfortable viewing distance. Ten control pictures were prepared by distorting or repixellating the two sets of ten photographs so that no clear structure was visible although overall luminance and colour range was the same for the familiar faces and the scrambled images. The scans were presented in random order for 12 seconds each. Both Kate and the control subject were told to 'look at the face and think about the person' or 'look at the image' as appropriate.

A significant change in regional cerebral blood flow (rCBF) during face perception was predicted in the posterior section of the fusiform gyrus particularly in the right hemisphere. This was found in both Kate and the control subject (Owen *et al.*, 2002). Figure 21.1 shows the scans of the brains of these two people including the amount of blood flow after the control pictures and after the familiar faces. It should be noted that there are no significant differences between the brains of Kate and the control subject. Owen *et al.* concluded that 'In spite of the multiple logistic and procedural problems involved, these results have major clinical and scientific implications and provide a strong basis for systematic study of possible residual cognitive function in patients diagnosed as being in a persistent vegetative state' (p. 394).

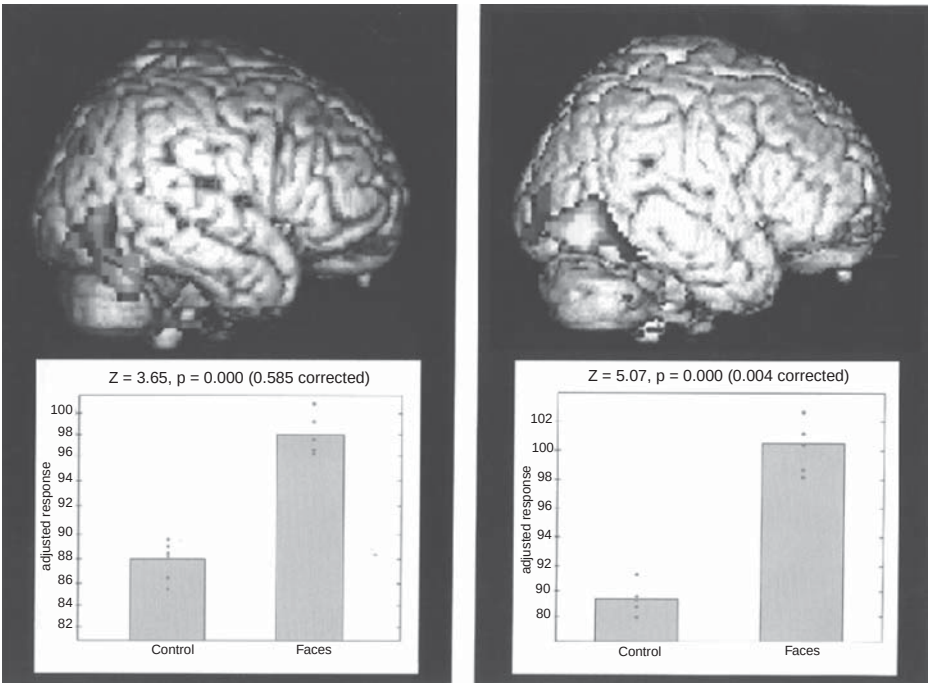

Figure 21.1 The PET scans of Kate (left) and an age-matched control subject (right). See also colour plate. Reproduced with permission of Elsevier Ltd.

Our first contact with Kate

The first we knew of Kate was an enquiry from the Encephalitis Support Group (now the Encephalitis Society) asking if we would see her for an assessment. After a telephone call we learned that Kate already had a psychologist at a hospital in Cambridge. We felt it would be difficult to see her given there was a psychologist involved in her care and it would look like interference if we saw her. A few weeks later there was an enquiry from a local home for people with severe physical disabilities saying Kate was there for respite care and they would like an assessment of her cognitive functioning. It was difficult for them to know Kate's intellectual level. Another telephone call followed explaining about the psychologist in Cambridge. The nurse in charge said she had spoken to him and he had no objections to us seeing her so an appointment was made. On reading Kate's notes we learned that she had regained some awareness 5–6 months after the onset of her illness and 1–2 months after the PET scan. She was heard to say single words and phrases such as 'Don't like physiotherapy'. In May 1998, i.e. 11 months after the onset of her illness she was admitted to a rehabilitation centre where she spent 11 months. The psychologist there saw her twice. He said in his report that she appeared to be able to read quite well, she was oriented in place and time but had problems learning new things. She could speak single words but preferred to use a letter board. She was frequently agitated and distressed and this could have interfered with her performance. In April 1999 Kate was discharged home under the care of her parents where she has lived ever since. Every few weeks she spent two weeks in respite care. It was while she was there that we received the request to assess her cognitive abilities.

The first assessment lasted for 3 hours spread over two visits. One of us (BAW) went to the home one afternoon not quite sure what tests to take or how interactive Kate would be. She was in a wheelchair and used a letter board to communicate because of severe dysarthria. I had difficulty understanding her speech and needed the letter board. I explained to Kate that I had been asked to see her to assess her thinking, her memory, her concentration and things like that. I said I knew she had been in hospital in Cambridge and had seen a psychologist there. At the mention of the hospital Kate became very distressed and agitated. She was crying and groaning and said (via her letter board) that she hated the hospital. In an attempt to distract her, I opened the Raven's Standard Progressive Matrices (a non-verbal test of reasoning) and explained to her about the test. Very quickly she became engrossed in the task and worked out many of the solutions. I realized that Kate was brighter than I had expected and I had taken the wrong tests with me so I said I would come again in a few days with more tests. Kate agreed to this and was far less disturbed at the end of the session than she had been at the beginning. The next time Kate managed to complete a number of tests either through pointing to the correct answer/response or through spelling out the answers on her letter board. I avoided certain tests such as story/prose recall as I thought it would take her too long to spell out what she had remembered. Kate said she enjoyed doing the tests and I said I would write a report for the staff at the home and send a copy to her and her parents.

Results of the initial assessment

The tests given to Kate for this first assessment together with the results were:

1. The Ravens Standard Progressive Matrices (to assess non-verbal reasoning). She scored 37 from a maximum of 60, which placed her at the 25th percentile; this is in the average range.
2 Spot The Word (from the Speed and Capacity of Language Processing Test to assess premorbid ability). She scored 43/60 which gave her an age-scaled score of 8. This is in the low average range.
3 The Wechsler Adult Intelligence Scale-Revised (WAIS-R; verbal subtests only to assess verbal intelligence). The age-scaled scores on the individual subtests were:

    Information 8
    Digit span 8
    Vocabulary 7
    Arithmetic 6
    Comprehension 6
    Similarities 11

    Verbal IQ 86 (although this is low average and almost certainly below her premorbid level, it is not severely impaired)
4 The Rivermead Behavioural Memory Test (RBMT; to assess everyday memory: a shortened version was used with story and name learning omitted). Kate scored 16/18 which is in the normal range.
5 Wechsler Memory Scale-Revised (WMS-R): Visual Memory Span subtest. Kate scored 7/14 on the forward visual span and 6/12 on the backward visual span. These are low average scores.

6 Recognition memory for (1) words and (2) faces. For words Kate scored 41/50 which gave her an age-scaled score of 6 (low average) and for faces she scored 23/50 i.e. at chance level which was impaired.

My conclusions were that although the overall picture reflected a drop from her pre-morbid level, given that Kate had a history degree and had completed teacher training, none of the results were in the impaired range apart from the recognition memory for faces. There was no evidence that Kate had problems with memory for faces in real life and we know from the PET scan study that her recognition of familiar faces was apparently normal. At the very least, she was functioning in the low average range and for someone who had been vegetative/minimally conscious for several months this was surprisingly good. I also recognized that Kate was feeling distressed when first seen and this could have depressed her scores. She also had relatively poor vision so that material needed to be close to her or in large print for her to see it well.

Further assessments

In August and September 2000, Kate was reassessed. All the earlier tests were readministered on three separate occasions each lasting about one hour. Her mood at this time was much better. She could discuss what had happened to her without becoming distressed and spelled out on her letter board that she enjoyed doing the tests as it showed people she was not stupid. The Raven's Matrices Score was now 43/60 placing Kate at the 50th percentile. On Spot the Word, Kate had improved a little (46/60) giving her an age-scaled score of 10 (average). Her verbal IQ had improved by 3 points. She had also improved on most of the memory tests. Her RBMT score was unchanged but she had increased her scores on the Recognition Memory Test and on the WMS-R. On recognition of faces, Kate was above chance but still below the 5th percentile. Her forward digit span was now at the 90th percentile and her backward span at the 59th percentile.

Additional tests were given to Kate over the following year. We gave her tests of face recognition, recognition of emotional expressions, a naming test and two tests of executive functioning. In comparison with age-matched controls Kate had some difficulty with the recognition of emotional expressions, particularly with disgust and, to a lesser extent, with fear and surprise. (In 2001 when this test was readministered, Kate scored in the normal range for all emotional expressions.) She recognized famous people and famous landmarks (these tests are described in McCarthy *et al.*, 1996) however, she was in the average range on a naming test and was above average on the two executive functioning tests; on the Modified Card Sorting Test she scored 100% and on the Brixton Spatial Anticipation Test she scored in the high average range. Thus her problem-solving ability and her ability to 'keep on track' would appear to be good.

These results were encouraging. A young woman who had been in a state of severely reduced awareness for several months showed considerable cognitive recovery. Her test results were, by and large, in the average range despite her considerable physical disability and her severe dysarthria. Less than 10% of people recover awareness after prolonged periods of being vegetative following non-traumatic causes (Giacino and Kalmar, 1997). Although results were better for people who were minimally conscious, this was particularly true for those who had sustained a traumatic brain injury (TBI) (Kate had sustained acute disseminated encephalitis). Giacino and Kalmar (1997) report performance on the Disability Rating Scale for the clients in their study but do not report detailed cognitive

assessment scores. Kate seems to have done well cognitively, almost certainly because the damage was mainly confined to the brain stem and not the neocortex. After the assessment in September 2000, Kate asked me for a letter to summarize the results. I wrote the following letter that still travels everywhere with Kate.

November 10 2000

To whom it may concern

> Kate Bainbridge was taken ill with an infection of the brain in 1997. For about 6 months she remained in a minimally conscious state. This means she was able to open her eyes and showed a sleep/wake cycle but could not communicate, respond to situations or show evidence of thinking. Since that time Kate has made considerable progress, indeed she is fairly unusual in showing such good recovery in her thinking and memory. People who are so severely impaired for so long rarely achieve the level Kate has attained. She is to be congratulated for achieving so much.
>
> Although Kate is severely physically disabled and has difficulty with her speech, her thinking and reasoning skills are within the normal range. It is easy for people to underestimate her intelligence given her speech and motor problems. This is likely to prove frustrating for Kate and may well make her angry.
>
> For someone in Kate's position, it is important to have consistency in her life and for her to be cared for by people she can trust and who understand her problems. Anybody who has sustained an injury to the brain is likely to weep more readily, to become fatigued more easily and to find certain situations frustrating. Given Kate's dependence on others for physical care and her need to communicate with her board, these tendencies are likely to be exacerbated. She will probably respond best to understanding and approval rather than criticism.
>
> In many ways Kate is a remarkable young woman given how far she has come since those first six months after her illness, and she needs opportunities to show her intellectual capacities.
>
> Barbara A. Wilson

The views of Kate and her parents

Kate was certainly appreciative of the assessments and the letter. Kate was very angry at her treatment in hospital. When I first knew her she was angry. Her parents talk about her anger and this soon became a focus of our treatment. In October 2000 she sent me a letter saying:

> Thank you so much for the assessments they treated me as if I was stupid in [hospital]. My stay there was absolute hell they never told me any thing. They used to suction me through my mouth and they never told me why or what it was called they have never told me about my trachy [tracheostomy tube]. I am lucky I am with it and have a good memory so I could work it out. I don't want them to do it to anyone else. They have learnt a lot from me already, but I think telling people what you are doing is very important. I can't tell you how frightening it was especially suction through the mouth. I tried to hold my breath to get away from all the pain. They never told me about my [feeding] tube. I wondered why I did not eat.

Around this time I told Kate about her PET scan and how important it was in the field of imaging and studies of people in a vegetative or minimally conscious state. One day, Adrian Owen, one of the authors of the paper about Kate's PET scan was visiting the home

where Kate went for respite care. He was there at the same time that I was visiting Kate. I introduced her to him and they discussed the scan. Soon afterwards Kate wrote me another letter saying

> It was really nice to see you and it was good to hear about my brain. I knew I was OK I just needed someone to agree with me. I have been really thinking about it and it is just becoming clear what this illness has done to me. It is just becoming clear that I will never have children which is very hard to cope with anyway I never want to go into hospital again.

Early in January 2001, I received another letter from Kate saying

> Thank you so much for the letter about me it will really help. I knew I was OK my memory has been fine since the end of October 1997. I can remember the physio asking me why I made so much noise. Well I was screaming as they caused me so much pain. I don't want anybody to have the same awful time as I did. I think my case shows you don't treat people as text book cases. You need to be told where you are every day for a few months and make sure they can hear you. It sounded just like noise to me even though my hearing tests showed no hearing loss. It is really frightening not knowing where I was or why I was there. No doctor ever told me about my illness. They are lucky I am with it I worked it all out.

Kate said to me recently that they treated her as a body and not a person and had no hope for her. Her mother said that everyone was very kind in the first hospital but did not know what was wrong. In the second hospital in intensive care they were told they could ring any time day or night so they felt involved. After about four or five weeks Kate was moved to the specialist head injury ward and although the staff were always willing to talk and were honest with you, there was no sense of excitement. She went on to say

> When I told them that Kate moved her fingers today they said not to read too much into that as babies move their fingers. I felt distressed about that. Once I got angry with them and said they shouldn't talk about Kate as if she wasn't there. She had speech and OT and we were trying to communicate. She had no facial expression. We tried blinking and couldn't get that right. Then we used a Yes/No board and then her sister came and brought a big pad with felt tip pens and we wrote things like 'We love you'. We discovered she hated TV. We'd put it on when we left thinking it would provide some company but she hated it. Kate said at this point, 'I couldn't hear it'. For a long time Kate heard noises but could not understand speech.

Her mother continued

> I would wheel her round the hospital holding Kate's head up with one hand and pushing the wheelchair with the other. Sometimes we would be crying.

Kate's father said that on one occasion he told one of the staff that he was thinking of buying a computer for Kate and was told that there wasn't much point. The computer now of course is crucially important for Kate. In contrast, one of the senior nurses there said to Kate's parents 'Never give up' and when Kate went to rehabilitation they had a very good social worker for a time so it wasn't all bad. Indeed the family feel they had some good treatment but so many things were not dealt with well. They have certainly had to battle to move forwards.

Helping Kate with her emotional problems

Kate wrote a paper with us on 'Cognitive recovery from *persistent* vegetative state' (Wilson *et al*., 2001). Since 2000, Kate has been seen by several clinical psychology trainees each of whom were spending a few months with me as part of their training. These people provided help for the emotional difficulties Kate was facing. Three of them, Jamie MacNiven, Rebecca Poz and Fergus Gracey together with Kate and I, published a paper on some aspects of this treatment (MacNiven *et al*., 2003). Other trainees, Emma Berry, Emily Miller and Sarah Ronaghan, have continued working with Kate since then. Emotional difficulties are common after brain injury. Anxiety, depression, post-traumatic stress reactions and anger are frequently seen; cognitive recovery may be hindered by emotional difficulties; behaviour problems may increase and the treatment and management of emotional difficulties is an essential part of neuropsychological rehabilitation (Prigatano, 1999). Without such treatment we are likely to reduce the chances of successful rehabilitation. The emotional consequences of brain injury are due to at least three main causes (Gainotti, 1993): first, they may arise as a direct result of neurological damage (for example, brainstem damage can lead to emotional lability); second, they can arise from psychological factors (for example, impaired cognitive functioning such as poor memory can lead to reduced self-esteem) and third, they can result from psychodynamic factors (for example, social isolation following brain injury can lead to depression). Each of these factors could have contributed to Kate's problems. Treatment involves careful assessment and an appreciation of several theoretical models as outlined in Chapters 13 to 20 of this book.

During her first few months in hospital Kate had several chest infections. She also showed signs of spastic paraparesis with reduced muscle power in all groups and evidence of hyper-reflexia. Consequently, the main focus for this period of rehabilitation was physiotherapy, which, as we saw earlier, Kate found frightening and painful. Behavioural difficulties, including screaming and occasional biting, were recorded but no one offered help with the cognitive, emotional and behavioural problems.

Once the cognitive assessment had been carried out and it was clear that Kate was functioning better than expected by many of those working with her, we realized that we should try to help her deal with the emotional problems. Kate's psychological reaction to her illness was considerable. Premorbidly, Kate was reported by her family to have been very bright, kind, shy and quiet. She had achieved a good first degree, followed by a post-graduate teaching qualification. Kate had been in a long-term relationship with her boy-friend. They had just bought a house together and had plans to marry. Although Kate's teaching job was not as enjoyable as she had wanted, she had plans to continue her job in teaching. Her parents and family were close. Kate was a young woman who had been thinking about her future and who had a happy life.

Following her illness, Kate's relationships, employment, social existence and identity had all altered. At a stage when she had been thinking about marriage and a family, her illness appeared to have changed everything. Not surprisingly, Kate was experiencing low mood, anger and anxiety reactions that reflected the shocking change in her circumstances.

During her time in rehabilitation and while on respite, Kate presented as withdrawn and depressed. She was prone to screaming, especially during physiotherapy and was known to bite other people – often this would be when others would be helping with her

personal care. From a behavioural perspective, Kate's behaviour could be seen as an attempt to communicate to those providing her care that she was frightened and in pain. Kate's difficulties with communication and her reliance upon a communication board often resulted in frustration for her and her carers, as misunderstandings would be common.

Since her original treatment in hospital, Kate had begun to feel very angry about the way she felt she had been treated. This became a dominant theme in her discussion of what had happened to her, persisting for a number of years. At the beginning of the assessment to determine the factors contributing to the anger and low mood Kate said:

> Everyone thinks they [the hospital staff] are good, but even my medical care got worse and worse. I think they are useless except in intensive care…I thought they just enjoyed hurting me [during suction] and scaring me as they took no notice of my screams. Can you see how angry I am? In my last illness I got a collapsed lung and pneumonia it was their fault.

This anger and frustration that Kate felt was also at times directed towards her family and friends and towards herself:

> I have just met an old friend from Uni and it really upset me. I can now see how much I am missing. She has been married for five years and she has a house and a life…I just scream as I can't cry which I would do if I could…I hate feeling guilty. I was carefree before and now I rely on others.

From a cognitive-behavioural perspective, Kate's depression could be seen to involve suicidal ideation, a sense of worthlessness and a pattern of negative thinking, feeling, behaviour and physical sensation.

It was clear that Kate's insight into the changes in her life was increasing and with it the realization that she had lost a great deal. The enormous task of beginning to recognize the changes in her life now and in the future was beginning to become clear to Kate at the point at which she began therapy. Kate reflected:

> I feel depressed as it will be ages before I can get married. If I ever can…I also know that I will never be well enough to have a baby, which is very hard to cope with as I used to want lots… I also feel guilty as I know I am hard work.

Formulation

In formulating the psychological distress that Kate was experiencing, it was hypothesized that the environmental factors such as her continued interaction problems with carers, and internal factors such as her pattern of negative thinking and behavioural avoidance were keeping Kate focused on the past and on what she had lost. It was as if Kate was stuck in the trauma she had experienced and was overwhelmed with this loss of normality. Kate's self-esteem was low, now describing herself as 'stupid' and 'useless'. Formulation allowed for specific patterns of thinking and behaviour to be explored with Kate. We present in Figure 21.2 a diagrammatic representation of the obstacles to emotional recovery (i.e. the experiences Kate had and her reaction to these experiences) together with Kate's response and solutions to the problems that she found through therapy. Essentially she did this through focusing on her current identity, acknowledging the past but resolving to move on and focus on the present and the future. Figure 21.3 shows Kate as she was before her illness.

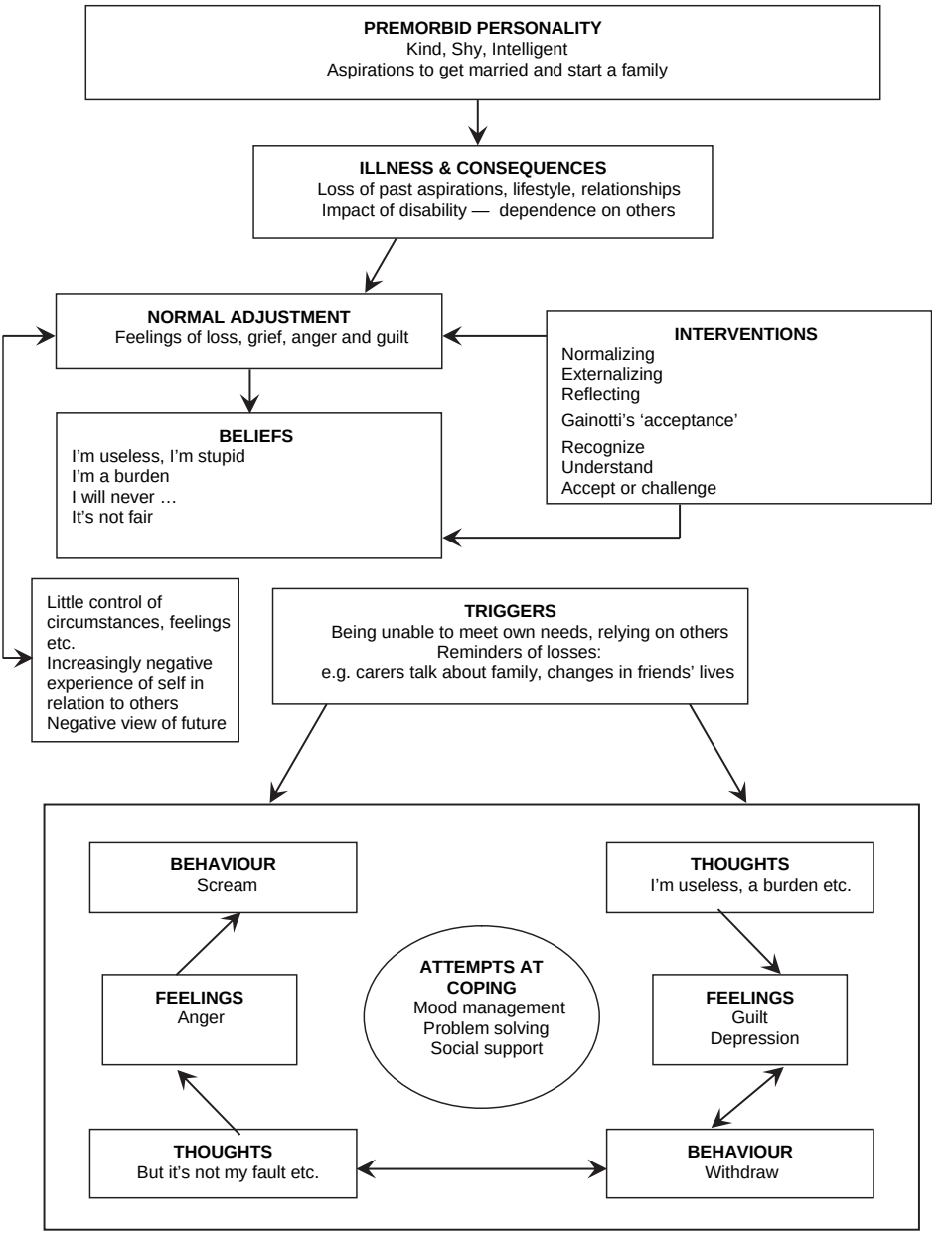

Figure 21.2 Formulation diagram.

Intervention

The main purpose of our intervention was to reduce Kate's distress and anger and to help her understand herself better. A key element of effective psychotherapy is the development of a therapeutic alliance. By collaboratively working with the individual, using the

Figure 21.3 Kate before her illness.

formulation as a basis for intervention, the therapist is able to encourage progress. In helping to develop this collaborative relationship, the therapist introduces a sound framework upon which the techniques of various psychotherapeutic approaches can be built.

Many individuals who experience brain injury do not have the opportunity to benefit from psychotherapy as part of their rehabilitation. Some people believe that brain injury is a legitimate reason for excluding someone from psychotherapy and cognitive problems may prevent 'carryover' from session to session. We disagree and would argue that the heterogeneous nature of brain injury is a good reason why formulation should be incorporated into an individual's comprehensive rehabilitation. By developing a detailed understanding of the individual's situation, from the person's perspective, a tailored approach to therapy drawing on multiple theoretical perspectives can be undertaken. The work undertaken with Kate involved elements and techniques from a number of such theoretical perspectives in an attempt to draw upon the strengths of each as they applied to Kate and her situation. The main specific problems faced by Kate, the goals in addressing each problem, the interventions used and the outcomes of each approach are illustrated in Table 21.1.

Personal construct theory (Kelly, 1955) was used to help Kate characterize herself in the present as opposed to reliving the past as a perpetual present. This particular approach enables the individual to create his/her own ways of seeing the world, and reduces the feeling of being a passive recipient of imposed ideas or perspectives. 'Constructs' are templates about the world that the individual holds and adapts as life's realities are experienced. Therapy using these ideas encourages the individual to develop new ideas about themselves in the world (Blowers and O'Connor, 1995).

Table 21.1. Problems, goals, interventions and outcomes

Problem	*Goal*	*Intervention*	*Outcome*
1. Persistent feelings of loss, grief, anger, guilt and depression	Alleviation of enduring emotional impact of hospital experience	Cognitive therapy focusing on identity and acceptance; facilitation of 'normal adjustment'. Instruction in practical anger management techniques	Frequency of references to hospital experience significantly reduced in sessions over period of six months (e.g. each of first three sessions focused almost exclusively in 'what they did to me' – final three sessions focusing on 'who I am now and what the future holds'). Follow-up confirms maintenance of gains made. Reframing of self-identity without reference to hospital experience. Subjective self-report of feelings identify minimal anger and guilt. Objective report of family and carers supports much less anger and grief feelings in Kate's references to hospital experience
2. Behavioural consequences of anger, guilt and depression (e.g. anger towards carers, withdrawal)	Development of more constructive interaction between Kate and carers	Empathy work with Kate – identifying phrases or attitudes hurtful to Kate and problem-solving strategies to communicate these feelings to carers without anger (e.g. showing carers published paper about Kate with her quotes about hurtful comments)	Self- and carer-reports of increased understanding between Kate and carers. Evidence of Kate using strategies in conflict situations with success (e.g. asking carer to change subject if discussing children without becoming angry towards carer). Strategies enable Kate to continue interaction, reduce frequency of withdrawal and feel more positive towards carers

Table 21.1. (cont.)

Problem	*Goal*	*Intervention*	*Outcome*
3. Negative self-beliefs (e.g. 'I'm stupid, I'm worthless')	Objective exploration of validity of negative beliefs that maintain depressive ideation	Personal construct theory, narrative therapy and Mindfulness techniques used to focus on self in present with additional cognitive work to challenge some new beliefs/thoughts	Self-report of higher self-esteem. Positive self-regard evidenced by increased plans for the future. Determination to focus on the present and the future – acknowledging the past but leaving it in the past. Development of new set of beliefs (e.g. 'I'm not stupid. My experience has not been for nothing. I can help other people with similar problems')
4. Loss of control and independence	Increase in independence and control	Family's own interventions including own 'flat' within house	Reinforcement of therapeutic work. Confirmation of new beliefs and thoughts about self and future. Enhanced quality of life

Anger management techniques (Demark and Gemeinhardt, 2002) combined with cognitive therapy (Segal *et al.*, 2002) allowed Kate to focus on specific patterns of thinking while also clarifying her present identity. Interpersonal problem-solving work (Malia *et al.*, 1995) focused on developing Kate's ability to empathize with others, especially her carers with whom there had been some difficulties. This potentially challenging work was possible mainly because of the quality of the therapeutic alliance between Kate and her therapist.

Using ideas from narrative therapy (Nicholson, 1995) and mindfulness techniques (Segal *et al.*, 2002), again combined with cognitive work, enabled Kate to focus more on the present and to think realistically and optimistically about her future. Further problem-solving work looking at specific 'problem situations' enabled Kate to interact more successfully with carers. Kate reports:

> I can't believe how much I have changed. I now want to be alive and I am looking forward to the future … I can now keep myself occupied and busy, instead of sitting on my own doing nothing … I just don't want anyone else to have such an awful time as me, I can now see it is over and hopefully I will never have it again … Can you see how angry I used to feel, but now there is no point in being angry, I just need to look to the future.

The role of Kate's family in her emotional recovery must not be underestimated. In the context of a highly supportive and understanding family, Kate was given the chance to adjust. Without this support it is unlikely that Kate could have recovered to the extent that she has. In fact, it is certain that this was the most important protective factor that prevented Kate from having a much worse experience and contributed very significantly to Kate's cognitive and emotional recovery. It is vital that families are given the support they themselves need in order that they can positively influence the outcome of the person who has sustained a brain injury (Tyerman and Booth, 2001). As Kate says:

> I am very lucky to have my Mum and Dad. I just feel so sorry for people who don't have my Mum and Dad they will be on their own in hospital with no one to look after them I am just glad I had Mum, Dad and my boyfriend to be my friends … They do so much for me and keep me laughing…My Dad says I am well trained as I laugh at his jokes…I can now laugh at my problems, mainly with my Mum and Dad as they know I am a clever turnip.

Using the model of rehabilitation described in Chapter 1 an appreciation of the emotional factors involved in Kate's ultimately successful emotional and cognitive rehabilitation was important. Kate's rehabilitation has taken several years and there is still a way to go. She has recently started to attend a day centre for people with brain injuries. Kate likes going there. She particularly likes the special exercise bicycle designed for people with her particular physical disabilities. She goes one day a week but is hoping to increase this to two days a week if a nurse can be found to accompany her for the extra day. Kate has to have a person with her who can cope if she needs to be suctioned. As far as the neuropsychological intervention is concerned, Kate is seen every two weeks. We are still helping with her anger and self-esteem. Although problems in these areas have reduced, they sometimes reoccur. In addition, we are planning to help Kate become more independent outside her home. The current goal is to see if she is safe to go to and from the post office and how she will cope if her wheelchair gets stuck. If this is successful, the next goal will be to see if she can travel to and from the library independently. As this involves crossing a road, we need to balance the need for independence with the need to ensure Kate's safety.

The final word from Kate and her parents

Kate said to me a few days ago

> Before my illness I liked to be in control. I was happy and I had plans for my life which have all gone. My illness was a huge shock. I will never get over the shock. My life has totally changed.

When asked what she enjoyed doing now Kate said

> I enjoy my computer and e-mails and Teddy (Kate's cat). I like Feldenkrais physiotherapy. I have been having it for five years. It is what Christopher Reeve, Superman, has. I still love animals. I like pets, they give you a reason to get up in the morning. The most important thing for me was having a proper assessment and emotional help.

Kate's mother said

> Not to be assessed is like being unemployed, you are not part of the world. It is incredibly important. As a carer I remember Kate getting incredibly angry with everyone. We didn't know how to cope with it. Family and friends wanted to help and

> we had to say to stay away, don't visit. We didn't know if it would ever go away. Would I always be torn between my daughter and the rest of the family? The family **want** to help. They are devastated too, they say they understand but the hurt is still there. That was worse almost than the illness.

Kate's father said how angry he became when a doctor once asked him if Kate was always like that – angry all the time. He said 'Don't you blame Kate'.

Kate continued

> The help has made me normal again and brought back my sense of humour. Having people that understood was important.
>
> I used to want to die until I got emotional help.

I asked Kate how she saw her life in five years time. 'I hope Mum and Dad and Teddy are with me,' she said, but two days later she added to this with an e-mail:

> I was thinking about what I want in the future, I really like pets and animals so a dog would be really nice. It would be a friend. I used to have a dog and she was lovely, but very naughty. She used to make me cry, I was her pet! I really miss her and I would like another. I also would like a person to be with me, as you need to fight for everything. I can't see a man ever wanting me as I am so disabled, I will have to have a dog. I never want to live in a nursing home, I like to be in the world.

Kate, we hope you achieve these goals.

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Section 4
Chapter
22

Outcomes

Is this approach effective? Outcome measurement at the Oliver Zangwill Centre

Andrew Bateman

Introduction

Through the course of this book the approaches to comprehensive neuropsychological rehabilitation that have been discussed demonstrate numerous elements constituting an entire package of rehabilitation which can be described as holistic in its coverage. Outcome of rehabilitation may be conceptualized in terms of objective or observable changes in behaviour, or changes in subjective experience applied to either the client or family members. The focus of outcome measurement may be on the ultimate aims of rehabilitation (e.g. social participation-related goals) or the processes hypothesized to underpin change (e.g. awareness, learning compensatory strategy use, improved confidence, better family relationships). Methods of measurement may equally vary to include observation, questionnaire ratings, or experimental or standardized 'implicit' methods designed to elucidate non-conscious processes (such as cognitive and emotional processes).

Within the programme, the range of individual interventions requires a range of methodologies to address the different types of questions concerning effectiveness. Individual elements can be subject to specific outcome evaluations, as illustrated in Chapter 6 about attention and goal management. Similarly, individual patient outcomes can be examined, as illustrated in the case studies. As discussed in our case study chapters, however, the individual elements assessed in the context of a holistic programme need to be seen as parts of the whole process and this means that it is often hard to isolate the efficacy of individual elements.

Studies that have evaluated comparable comprehensive holistic cognitive rehabilitation programmes include Parente and Stapleton (1999); Salazar *et al.* (2000); Klonoff *et al.* (2001); Malec (2001). These papers were also cited by Cicerone *et al.* (2005) who concluded (p. 1686) that Salazar's class 1 study was supportive of an organized programme for those with more severe injuries. It has been noted that it is difficult to generalize from this study as it was limited to military personnel. The other studies listed here provide evidence of benefit regarding community integration, social participation and productivity.

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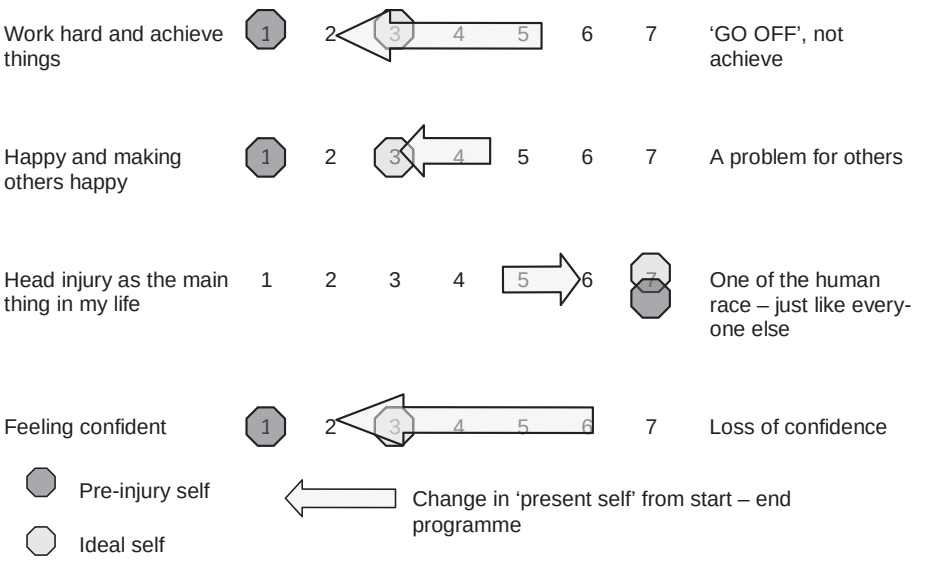
Work hard and achieve things
1 2 3 4 5 6 7
'GO OFF', not achieve
Happy and making others happy
1 2 3 4 5 6 7
A problem for others
Head injury as the main thing in my life
1 2 3 4 5 6 7
One of the human race – just like every-one else
Feeling confident
1 2 3 4 5 6 7
Loss of confidence
Pre-injury self
Ideal self
Change in 'present self' from start – end programme

Figure 22.1 Extract of a personal construct questionnaire developed by four clients. The markings indicate the position of rating of 'pre-injury self' 'ideal self' and 'present self' on a continuum where the poles are devised with the clients. This client moved towards his 'ideal self', exceeding, this rating in two items, moving towards his pre-injury ratings of himself.

In arguing for provision of an intensive programme, it is appropriate that we also examine outcomes of the programme in its entirety. With the data available to us we can only answer questions specific to our own setting. Wider questions such as 'Is this programme more effective than another type of programme?' or even 'Could you achieve the same outcomes in a shorter period?' await the opportunity to conduct long-term multi-centre studies. For now, however, these questions, demanding quantitative methodologies, are clearly unanswerable using our own data in isolation. Evidence for components of the programme (such as the Attention and Goal Management Group) has been drawn from elsewhere: evidence for the individual interventions provided, in the absence of published evidence, invites a systematic approach based on individual formulations such that interventions are tested 'live' during our work with the client. In our approach we have attempted to justify each component and evaluate the process as well as the outcome. Through all of this we face the challenge of keeping sight of the uniqueness of individual's goals and their meanings.

We also wish to emphasize that quantitative approaches to service evaluation are not the only ways of capturing the sense of benefit that patients report, and for this reason we also include a short section on what our clients say about their experiences. Research under way at Oliver Zangwill Centre (OZC) for Neuropsychological Rehabilitation is providing a new assessment of how people with brain injury see themselves using 'personal constructs'. It is best illustrated with reference to Figure 22.1. This shows a few items selected from an example rating scale that the clients create in small groups. They are facilitated to develop a number of bipolar items pertinent to themselves and their group. The individuals discuss the two poles of any constructs that capture their experience such that they can map their 'present', 'ideal' and 'pre-injury' selves on the same set of continuua. In laying out the Y-shaped model (see Chapter 4 (Figure 4.1), p. 50) we have argued that by engaging people in the process of change

we reduce their sense of discrepancy between current and ideal self in themselves and in society. A qualitative analysis of the constructs elicited in a sample of clients who have attended the programme is described in Gracey *et al.* (2008). Administered individually to clients at the start, mid-point and end of rehabilitation, and at follow-up, this allows us to assess changes in individual sense of discrepancy through the programme and beyond. We aim to record the process of change alongside recording information about goal attainment. This process involves topics beyond the scope of this chapter such as evaluation of self-esteem, changes in awareness, relationship functioning, wellbeing and autonomy and reduction of distress. Attending to processes hypothesized within the Y-shaped model means that we need to observe the relationship between improving skills, improving confidence, and these emotional adjustment components. A further description of the use of this personal construct assessment can be found in Dewar and Gracey (2007). Qualitative studies of identity changes following brain injury and in neuropsychological intervention are also well represented in a special issue of the journal *Neuropsychological Rehabilitation* dedicated to this topic (Gracey and Ownsworth, 2008).

Using published questionnaires to evaluate programme impact

Selection of appropriate outcome questionnaires clearly needs to be determined by the characteristics of the population under study. Forms such as the Barthel Index and the Functional Independence Measure (FIM) would not be sensitive for our clients who would, in the main, have ceiling scores on these measures before our programme starts. That is not to say that they are not experiencing significant persisting sequelae of acquired brain injury, simply that they have made good progress against the domains covered in these measures.

One of the questionnaires used at OZC is the European Brain Injury Questionnaire (EBIQ), a 63 item tool that provides information on the subjective experience across nine domains. It has been demonstrated to be reliable and valid for brain injured groups (Teasdale *et al.*, 1997; Sopena *et al.*, 2007). At the preliminary appointment participants and their relative/carer are asked to complete the self-rating and carer-rating versions of the EBIQ. These measures are then repeated at the end of the rehabilitation programme. The OZC team has, from the founding of the Centre, collected these findings into a database of outcome data that includes the primary outcome measure of goal attainment and item-by-item responses to EBIQ. The data we have collected have enabled us to address the following simple questions:

- What goals are important to our participants?
- Do clients attending the programme attain the goals that have been set?
- Do questionnaire responses change over the time course of rehabilitation?
- Is there a relationship between goal attainment and responses to questionnaires?

Setting goals and service evaluation

As discussed in Chapter 3, setting goals with participants is a critical component in the admission to our intensive programme. The goals are essential in allowing us to provide direction to the interdisciplinary team, to enable participants to know if *they* are making progress as a result of being in the Centre and to provide the overall primary outcome

measure for the effectiveness of our work. The difficulties in evaluating rehabilitation have been widely discussed. However there have been some attempts to examine the contribution of packages of care. For example, Liu *et al.* (2004) contrasted the systematic audit tools that provide disability ratings (such as Barthel Index) with goal attainment as an indicator of participation (handicap). They concluded:

> …evaluation of long-term goal achievement and variances provides complementary information on rehabilitation process and outcome after brain injury over and above the use of conventional disability measures (p. 400).

We agree with this position and assert that the need for a client-centred goal setting process is a defining feature of holistic rehabilitation.

Box 22.1 Goal setting priorities*

Objective

This cross-sectional descriptive study was conducted in early 2005. It was undertaken to compare life goals in our out-patient client group with previously published data (Sivaraman Nair and Wade, 2003) from another centre that provides rehabilitation for clients earlier post-injury, and with more severe impairments. We felt that the Rivermead Life Goals Questionnaire was interesting because it appeared to have potential to support the process of goal setting, the prioritization of rehabilitation goals, and designing services to meet user needs.

Method

Relative importance of goal areas was identified with the Rivermead Life Goals Questionnaire.

Results

Thirty-seven clients (age 41+/–17 years; 11 female) were assessed during the survey period. Median time post-injury 24 months. The frequency with which goals were chosen as 'extremely important' was family 28, personal care 25, partner 25, family life 21, financial status 15, contacts 14, leisure 12, work 11, religion 10.

Conclusions

As previous research has shown, people with neurological conditions frequently attach great significance to relationships, personal care and domestic arrangements. Sivaraman Nair and Wade (2003) reported that work was extremely important to 20% and not at all important to 50% of their group of patients with chronic or progressive conditions. In contrast, work was extremely important to 30% of our group and not at all important to only 16%. Similar shifts in ratings were noted in other domains.

In comparison to the patients seen by Sivaraman Nair and Wade (2003), we found an increase in the frequency of 'extremely important' ratings with regard to work, religion or life philosophy. This observation is indicative that priorities do vary depending on the setting and time post-injury.

The findings attest to the utility and face validity of this short questionnaire. Furthermore, this study highlights the importance of a range of rehabilitation services to meet the needs of client groups who are at different stages in their recovery. In order to reflect the priorities of the OZC, we have since modified the questionnaire to add two further questions about the importance of psychological and physical wellbeing.*

*These data were originally a poster presented at Galway Satellite meeting of International Neuropsychology Society (2005), published in *Brain Impairment* (Bateman, 2005).

OZC procedures for setting goals

On our referral form we ask the referrer 'What do you think *your client* will gain from attending?' This is the first step in our method for setting goals. As such it highlights that there are various stakeholders in the goal setting process (referrer, relative, participant, society in general).

From the first face-to-face encounter with the OZC, participants are encouraged to engage in this process of identifying goals for rehabilitation. They are asked the simple open-ended question of 'What do *you hope* to gain from rehabilitation?'

As a supporting mechanism at this stage, in the last few years we have also included the Rivermead Life Goals Questionnaire (Sivaraman Nair, 2003, see Box 22.1), as a way of indicating the relative importance of the domains that could be considered within our rehabilitation programme. An analysis of data collected using this tool was conducted and enabled us to note that the priorities of patients with long-term neurological conditions shift as time post-onset increases.

Clients who appear to be appropriate for the rehabilitation programme return to the Centre for eight days during which they take part in interviews, psychometric and functional assessments ('detailed assessment'). During these eight days clients are set an open-ended task of reflecting upon, and writing in more detail about, their aspirations and goals for rehabilitation. In a related exercise they are asked to write about their strengths and weaknesses. Taken together these two tasks provide material for dialogue about whether to proceed to the intensive rehabilitation programme. Specific goals are discussed as relevant to each professional when they interview the client.

The information gleaned from the preliminary assessment appointment and these more detailed reflections are all used to build plans for the rehabilitation programme. Once the programme is under way the goals are revisited, and work with the individual programme co-ordinator enables the client to establish a set of 'SMART' (specific, measurable, achievable, realistic, timed) worded long-term goals. Progress through rehabilitation is then mapped against these goals, using our documentation procedure to note attainment of short-term goals that form the steps towards these longer-term goals.

For the purposes of database management, the goals are then categorized under the generic headings of 'understanding brain injury', 'managing daily activities' 'social and leisure activity' and 'vocational activity'. Examples of these categories of goals are provided in Table 22.1.

For some, especially if potential participants have reduced self-awareness, goal setting is a challenging task. It may reveal a lack of motivation to participate in rehabilitation. There is a need to take extra time to establish personally meaningful goals. It is worth noting, for outcome evaluation purposes, that a proportion of the goals set may not be achieved because of being unrealistic as a result of poor awareness. However, in such cases we endeavour to establish an 'experimental' approach to unrealistic goals, as set out in Chapter 4.

Method for evaluation of goal attainment

Although we have adopted a variance coding structure to map progress through the short-term goals towards the long-term goals, this has created a complex dataset that has not yet been evaluated in group analyses. Therefore, the question of programme efficacy is addressed simply, using the response categories of 'achieved', 'partially achieved' or 'not

Table 22.1. The main categories of long-term goals

Understanding brain injury
E.g. Show an accurate understanding of his/her difficulties and be able to explain these to two relatives and two members of the Centre staff
Managing daily activities independently
E.g. To be able to prepare a simple evening meal for the family on a weekly basis with supervision using identified strategies
Recreational activities
E.g. Will be engaged in two chosen leisure activities on at least a weekly basis (playing pool and woodwork).
Work or study plans
E.g. Will be engaged in a work trial and have an identified plan for return to paid employment within six months

achieved'. This categorization is discussed and agreed with the client at the end of the intensive and integration phases of the programme. Where appropriate we have also discussed goal attainment with clients at the follow-up review appointments.

Method for administration of questionnaires

Our preliminary assessment questionnaire is posted to participants approximately one month in advance of their one-day preliminary assessment appointment. They are asked to post the completed 20 page form to us in advance of the appointment. The form seeks to gather the participants' perspective on a wide range of topics including medical history, social history, vocational history, current difficulties, mood, physical function, language and communication, and goals. The 'goals section' of the questionnaire is shown in Table 22.2.

Results

Participant information

Data in the next part of this chapter relate to an analysis completed in 2005 of 95 participants (gender: 73% male). The age bands represented were ages 16–24, 19%; 25–34, 42%; 35–44, 22% and 45+, 17% (i.e. 83% of participants were under the age of 45). Aetiology of brain injury was: closed head injury 77%; cerebrovascular accident 8%; anoxia 6%, open head injury 3%; others 6%. Time (years) post-injury was as follows: <1 year, 15%; 1–2 years, 23%; 2–3 years, 15%; 3–4 years, 12%; 4–5 years, 14% and 5+ years, 21%.

Questionnaire data

Do outcome questionnaire responses change over the time course of rehabilitation?

The total scores of the EBIQ before and after rehabilitation (i.e. at week 24) are shown in Table 22.3.

Table 22.2. Questions about goals taken from the OZC preliminary assessment questionnaire
These questions are given in addition to the Rivermead Life Goals Questionnaire

What roles did you have prior to your brain injury? (e.g. family, work, leisure?)
What roles would you like to have in the future?
What does your relative/partner think?
What would you like to gain from any further assessment or rehabilitation? – Please list any goals you have.
Please ask a carer or relative to list any other goals (he or she) may have for any future rehabilitation.
What are the barriers to achieving your goals that you can identify?
What kind of help do you feel you need?

Table 22.3. Changes in total scores on Dysexecutive (DEX) and European Brain Injury Questionnaires (EBIQ)

Questionnaire	Median score at entry	Median score at week 24	Significance*
EBIQ self-rated	116 $N=80$	108 $N=46$	$P<0.01$
EBIQ independent rated	123 $N=79$	117 $N=35$	Not significant
DEX self-rated	31 $N=76$	24 $N=39$	$P<0.01$
DEX Independent rated	38 $N=73$	31 $N=33$	$P<0.01$

* using Wilcoxon signed ranks.

Goal attainment

Do clients attending the programme attain the goals that have been set?

Of 676 goals set for the clients 50 (7%) of these were not achieved. The remainder were wholly (47%) or partially (45%) achieved. The commonest goals, 248, were to do with managing activities of daily living with leisure goals, 154, coming second jointly with goals to do with understanding the consequences of brain injury and 119 goals being to do with work or study skills.

Is there a relationship between goal attainment and responses to questionnaires?

Self-rating EBIQ data at baseline was partitioned by quartiles, and frequency of goals attainment ratings was examined by visual inspection. High scores (>140) on the EBIQ were not associated with significantly higher rates of non-achievement of goals. In contrast, as may be predicted, low scores (<100) appear to be associated with a higher frequency of fully achieving goals (see Table 22.4).

Table 22.4. The relationship between self-rating EBIQ scores and goal attainment

EBIQ score at entry	Achieved	Partially achieved	Not achieved
Quartile 1 < 94	63%	36%	1%
Quartile 2 > 94 –116	40%	54%	6%
Quartile 3 > 117–140	39%	50%	10%
Quartile 4 > 140	43%	49%	8%

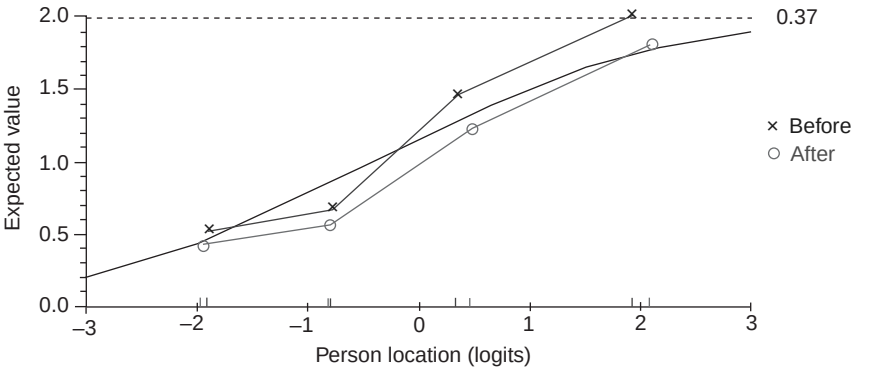

Figure 22.2 Legend Differential item functioning – before and after rehabilitation. Impact of rehabilitation on self-rated responses to EBIQ item 9, ('feeling hopeless about the future') uniform differential item function, $n=44$; $F = 4.12$, $P < 0.05$.

Conclusions on goal attainment and questionnaire research

Acknowledging the shortcomings of data presented, not least the drop-out in responses, in the three years since we completed this analysis we have renewed our efforts to ensure follow-up questionnaires are completed. We have found that this needs to be the dedicated responsibility of an assistant to track the follow-up questionnaires. Nonetheless, we believe that the data presented support the fact that the OZC holistic neuropsychological rehabilitation programme is effective in enabling participants to achieve their goals, and that this is indeed worthwhile.

We have also embarked on a systematic evaluation of the questionnaire data using modern psychometric techniques, namely Rasch analysis. Although a full description of this analysis is beyond the scope of this book (useful reviews of this approach can be found in Tesio (2003) and Pallant and Tennant (2007)), the preliminary findings have nevertheless proven to be very useful. The questionnaire's validity is demonstrated through examining the subscale properties. Individual questions have been examined. Perhaps of particular interest to one of the themes in this book is the subject of individuals' reported feelings of hopelessness after brain injury. Figure 22.2 shows a plot from the software package RUMM2020 that has been used to analyse the data from the EBIQ question 'Do you feel hopeless about the future?' This shows that this question is more

readily endorsed by patients before rehabilitation than afterwards. This observation applies to four ability groups that could be distinguished in this sample, producing what is described as a significant uniform differential item function ($P<0.05$) for this sample of patients.

What do the participants say to us?

Where possible we have tried to keep in touch with past participants. This has included invitations to a Centre Anniversary party each November, and more recently the establishment of a user group.

Clare, the wife of one past participant said:

> Five years on we still have regular times for menu planning, timetables, alarmed reminders, and the 'Nike strategy' [this was a term her husband coined with his psychologist to help overcome his inertia with a self-instruction to 'JUST DO IT']. He still resents it but if we don't do it's chaos – it helped that I was involved – that you switched the lights on – that I can understand the problems, not that they've gone away, but so that we have the ability to live with the problems.

Simon, 7 years on, showed me his credit-card sized 'list of goals for the month'. He has an established routine with his care support workers to help him keep on track. Care support workers have changed many times over the years (as might be predicted). For this reason part of the programme entailed training Simon and his mother to be in control in selecting, interviewing and directing the work of his care support workers.

One of the most powerful interventions occurs at the time of assessment before rehabilitation interventions have started. On this topic, Robert wrote:

> Staff found in me what I considered were positive characteristics. That discovery lifted my despair and helped me discover that there was, possibly, something fortunate about having survived the injuries…hope in place of despair.

Julie, post-encephalitis:

> the previous me has left me alone with only a vague memory of who I was, but some of your work has rifled through these a bit and made me look at things differently. It's not good living in what feels a completely different world – your team already understand…thank you.

Finally, a 'thank you' from Sally at the end of her programme:

> thank you for all your help, guidance and support. You have all, without exception made a huge difference to me, your unconditional acceptance and friendliness has meant a lot to me, and everything you have done has helped me achieve my goal – 'to be comfortable with myself'.

User group

The OZC has always had a tradition of keeping in touch with ex-clients, and ex-clients have their own tradition of keeping in touch with one another. We frequently receive postcards and letters from people, which are read out in the community meeting. Some clients come back to visit, or to revisit the skills they learnt as part of the rehabilitation programme. We have celebrated an annual Christmas Party, invitations are sent out to all past clients and we always have a good turn out. User involvement has become a key buzzword in research grant and service delivery policy.

In March 2005 some of the staff from the OZC went to a course run by Connect (www.ukconnect.org) – a charity focused on enabling people with aphasia to reconnect with their lives again. This inspiring training day was entitled 'Creative Solutions for Working with People with Stroke and Aphasia'. Connect facilitators described the consultation exercises that they had done, asking people with aphasia for their opinions on a variety of topics. Other workshops during the day encouraged lateral thinking about developing services. Discussion with colleagues following this training enabled us to see the potential for further work with our past clients.

We sent out a letter to all the ex-clients of the Centre who had completed the programme. We suggested a meeting date with the aim of finding out whether past clients thought that having a user forum was a good idea. We had a good response; many people wanted to be involved, some said that they could not come to meetings because they lived too far away – but still wanted to know what was going on – a few others said that they did not want any further contact and wanted to put the whole experience behind them.

The first meeting was a success, and the response to whether past clients thought it was worth having a user forum was positive. Many good ideas came out of the meeting, and the most striking thing about it was the enthusiasm and the energy that people had, and how much they wanted to contribute – or to *'give something back'* as some of them said.

The ideas that the group came up with were broadly in the following categories:

- Supporting current clients (which included future programme clients)
- Supporting relatives
- Information and education for other services
- Promotion and marketing of the Centre
- Feeding back to the Centre about the programme.

The structure of the meetings is still evolving. The user group said that they wanted a two-hour meeting, the first half hour to be for the group to make some decisions, then a couple of members of staff join them. They wanted to meet quarterly and decided in the first instance to meet without relatives, agreeing that inviting relatives to join them for one meeting a year might be helpful. In the second meeting the group began to take more ownership of the group, by chairing the meeting and taking minutes.

- The group decided to set up an internet forum to stay in contact with each other and discuss relevant issues.
- The group made some suggestions about how they could talk to current clients:
  - One of the local members was already meeting clients socially outside the Centre. He said that he would be happy to continue this and for us to tell clients.
  - They suggested compiling a list of contact details and a list of other services that current clients had found useful to give to clients when they had been in for an assessment so they could talk to past clients if they wanted to.
  - A number of people were keen to come to the Centre regularly to meet people who are here for the one-day assessment over their lunch-break. They set up a rota for a month to try this idea out.
- A couple of people arranged to contact a member of staff about marketing and fund-raising for the Centre.

- The group expressed emphatically the need to support relatives. They had some suggestions in addition to the support already provided by the Centre.
- Members of the group said that they would be keen to contribute to our teaching and workshops for professionals and carers.

The rehabilitation clients become members of this user group on completion of their programme. It is interesting to see that as this group has evolved it has given for some clients a meaningful point of ongoing point of contact with the Centre. They are positive about not having a sense of abrupt closure at the end of their programme, rather a transition to the next stage of their involvement with a service.

This is what some of the clients said about the last meeting:

> I felt that the meeting went well and I was pleased that everyone had similar views with regards to planning and ideas going forward!
>
> I think that the whole idea of a user group formed of clients who've benefited from the OZ system to be accessible to current and future potential clients is a very good one and I'm very pleased to be able to contribute myself.
>
> It was the OZ Centre that made me aware of my disabilities and showed me methods of compensating for them in a way that enabled me to lead a 'regular' life and return to work in my 'pre-accident' capacity.
>
> I'm very honoured to be able to 'chair' the meetings and still contribute to the meeting from an 'ideas' perspective; I was pleased that a couple of my idea were taken up by the organization of the current rehab programme; namely meeting the future clients during their assessment & the relatives of past clients meeting the current clients' relatives to pass on their experiences & advice!
>
> (Quotes past clients from the Oliver Zangwill Centre)

One of the most exciting things about the user group is the enthusiasm and commitment of the past clients to the Centre. It is a privilege as a member of staff to be part of the group and to witness the creativity and development of ideas from members.

Beyond individual client progress and outcome: observations on other outcomes of the Centre

The main activities of the Centre may be described under the headings of: (a) Assessments, (b) Rehabilitation, (c) Education, (d) Research and (e) Assistive technology.

Assessment

Over the first decade of the Centre's operation we have provided assessment and advice to several hundred individuals from a wide geographical area. A map showing the distribution of admissions is shown in Figure 22.3.

Research

The research activity of the Centre is best evidenced through the grants received to fund research and the many peer-reviewed publications that have contributed to the field of neuropsychological rehabilitation. At the time of going to press with this book, the Centre's tenth grant had just started enabling the employment of a research occupational therapist and research assistant. A list of research projects that have been funded at the Centre are shown in Table 22.5.

Table 22.5. Research grants at the Oliver Zangwill Centre 1996–2008

From Oxford and Anglian NHS Executive Research and Development Department £79 580 for a project entitled, The evaluation of a paging service for people with brain injury. (Wilson, B.A., Evans, J.J. and Emslie, H.) (2 years)
From Oxford and Anglian NHS Executive Research and Development Department £40820 for a project entitled, Which memory impaired people make good use of compensatory strategies? (Evans, J.J., Wilson, B.A. and Brentnall, S.) (2 years)
From NHS Executuive Research and Development Programme £93642 for a project entitled, Helping people with memory impairments recall facts and procedures: A comparison of two computer aids for personal information management. (Wright, P., Wilson, B.A., Evans, J.J. and Emslie, H.) (2 years).
From PPP Healthcare £144000 for a project entitled, MemoJog – an interactive memory aid to support independence among older people. (Newall, A.F., Evans, J.J., Gregor, P. and Hine, N.) (3 years)
From NHS Executive Research and Development Programme £99 058 for a project entitled, Identifying and understanding divided attention deficits in people with brain injury. (Wilson, B.A. and Evans, J.J.) (3 years)
From West of Scotland NHS R&D Consortium £39 223 for a project entitled, Rehabilitation of the dysexecutive syndrome: Investigations of the use of periodic auditory alerting to improve prospective remembering and goal management after brain injury. (Evans, J.J., Manly, T. and Kersal, D.) (1 year)
Norfolk Suffolk and Cambridge Strategic Health Authority £8996 for a project funded through the Practitioner Enterprise Award Scheme in Research and Learning (PEARL) on Rasch Analysis of Centre Outcomes. (Bateman, A.) (2 years)
From Chief Scientist Office £14988 for a project entitled, Improving Cognitive–Motor Dual Tasking in Neurological Illness. (10 months)
From Neurosciences Foundation £11450 for a project entitled, A functional magnetic resonance imaging (fMRI) study of goal management activity. (Cullen, B., Evans, J.J. and Brennan, D.) (6 months)
From National Institute for Health Research, Research for Patients Benefit Programme, £249611 for a project entitled, A randomized control trial of the impact of electronically delivered 'content-free' cueing on psychosocial functioning following brain injury. (Gracey, F., Wilson, B.A., Manly, T., Bateman, A., Fish, J., Malley, D and Evans, J.J.) (3 years)
Total grant income to date, £781368

Education

Each year the Centre has hosted a range of educational workshops that has attracted clinicians throughout the UK. Staff have been invited to chair symposia at the International Neuropsychological Society. Barbara A. Wilson was president of this Society in 2006–7, a year when the activities and focus of the Society was on rehabilitation. In the UK, the British Psychological Society (Division of Neuropsychology), College of Occupational Therapy (neuro section), The British Association of Behavioural and Cognitive Psychotherapies, and the Chartered Society of Physiotherapy has seen members of the OZC team take prominent roles in teaching and dissemination of our work.

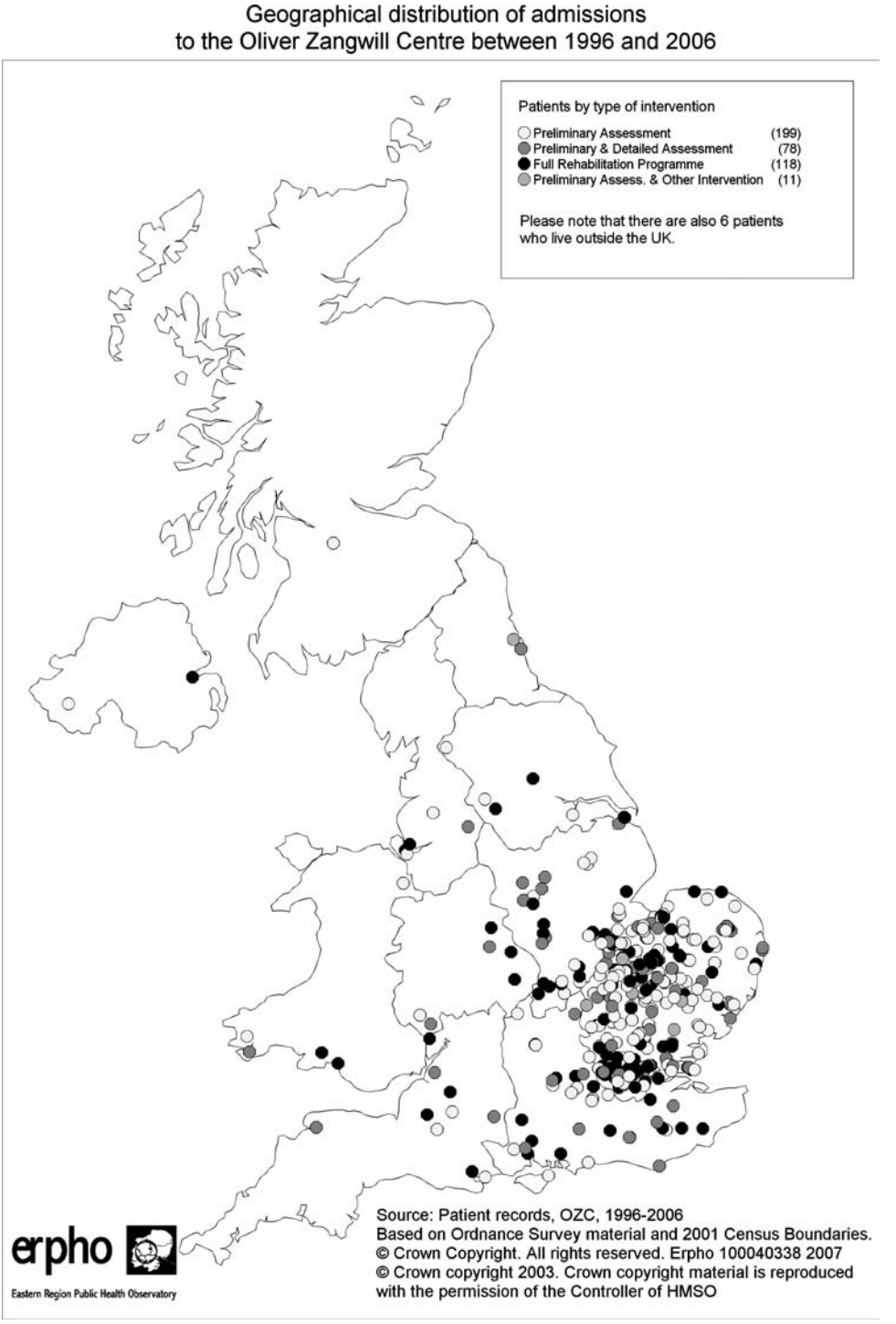
Geographical distribution of admissions
to the Oliver Zangwill Centre between 1996 and 2006
Patients by type of intervention
Preliminary Assessment (199)
Preliminary & Detailed Assessment (78)
Full Rehabilitation Programme (118)
Preliminary Assess. & Other Intervention (11)
Please note that there are also 6 patients
who live outside the UK.
erpho
Eastern Region Public Health Observatory
Source: Patient records, OZC, 1996-2006
Based on Ordnance Survey material and 2001 Census Boundaries.
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Figure 22.3 Geographical distribution of admissions to the Oliver Zangwill Centre between 1996 and 2006. Reproduced with permission. See also colour plate.

Table 22.6. NeuroPage™ publications

Emslie, H., Wilson, B.A., Quirk, K., Evans, J.J. and Watson, P. (2007). Using a paging system in the rehabilitation of encephalitic patients. *Neuropsychological Rehabilitation*, **17**(4/5), 567–81
Evans, J.J. and Wilson, B.A. (2003). Who makes good use of memory aids? Results of a survey of people with acquired brain injury. *Journal of the International Neuropsychological Society*, **9**, 925–35
Evans, J.J., Emslie, H.C. and Wilson, B.A. (1998). External cueing systems in the rehabilitation of executive impairments of action. *Journal of the International Neuropsychological Society*, **4**, 399–408
Fish, J., Manly, T., Emslie, H.C., Evans, J.J. and Wilson, B.A. (2008). Compensatory strategies for acquired disorders of memory and planning: differential effects of a paging system for patients with brain injury of traumatic versus cerebrovascular aetiology. *Journal of Neurology, Neurosurgery, and Psychiatry*, **79**, 930–5.
Fish, J., Manly, T. and Wilson, B.A. (2008). Long-term compensatory treatment of organizational deficits in a patient with bilateral frontal lobe damage. *Journal of the International Neuropsychological Society*, **14**(1), 154–63
Wilson, B.A., Evans, J.J., Emslie, H.C. and Malinek, V. (1997). Evaluation of NeuroPage: a new memory aid. *Journal of Neurology, Neurosurgery, and Psychiatry*, **63**, 113–15
Wilson, B.A., Emslie, H.C., Quirk, K. and Evans, J.J. (1999). George: learning to live independently with NeuroPage. *Rehabilitation Psychology*, **44**(3), 284–96
Wilson, B.A., Emslie, H.C., Quirk, K. and Evans, J.J. (2001). Reducing everyday memory and planning problems by means of a paging system: a randomized control crossover study. *Journal of Neurology, Neurosurgery, and Psychiatry*, **70**, 477–82
Wilson, B.A., Scott, H., Evans, J.J. and Emslie, H. (2003). Preliminary report of a NeuroPage service within a health care system. *NeuroRehabilitation*, **18**(1), 3–8
Wilson, B.A., Emslie, H., Quirk, K., Evans, J. and Watson, P. (2005). A randomized control trial to evaluate a paging system for people with traumatic brain injury. *Brain Injury*, **19**, 891–94.

More extended educational activities have been provided through supervision and training during placements for many clinical psychology, occupational therapy and speech and language therapy trainees. We have offered a Visiting Scholar scheme that has entailed individuals coming and working with us for the full 12 weeks of a programme. This has meant that we have welcomed colleagues from around the world, including Colombia, Hong Kong, Thailand, Switzerland, Italy, Spain and Germany.

Assistive technology

The NeuroPage service grew from a funded research project into a national clinical service built on the systematic research by Wilson *et al.* (a list of the papers published about NeuroPage can be seen in Table 22.6). NeuroPage continues to operate as a successful small business element of the Centre. Over the last few years we have on average maintained approximately 30 patients at a time receiving their daily schedules via pagers supervised by an administrator in the Centre. The most recent case study publication (Fish *et al.*, 2008) was identified by Grafman (2008) as illustrating 'output from one of the few centers in the world doing systematic research in order to find novel techniques that significantly and reliably improve outcome in patients with executive function deficits due to brain damage.

More of these kinds of centers…is needed' (p. 152). Our most recent significant grant award is to test the principles of 'content free cuing' delivered via mobile phone on achievement of day-to-day tasks, and the plan is to extend findings from this study to further develop our provision of assistive technology.

Conclusions

Finally, it is also appropriate to consider the wider outcomes of an institution such as the OZC. In a recent interview with Sheila Bremner, one of the founding members of staff, she recalled how opening the Centre in 1996, even experienced neurological rehabilitation clinicians did not have a language of neuropsychological rehabilitation. Ten years on, while the service continues, to our knowledge, to be unique in the UK in terms of the overall package of care that is offered, neuropsychological rehabilitation is now more frequently part of the agenda at a service description level. So we believe that through the research and education activities of the Centre we have had an impact on service provision that has had a beneficial outcome beyond the clients we have seen. Certainly, it is the aspiration of the team currently in post to continue to innovate, research and disseminate the activities of this Centre.

Looking ahead

The present research strategy of the Centre has three main strands:

1. To continue to develop an improved understanding of outcomes and outcome measurement. The track record in developing new assessments continues with ongoing work on the psychometric properties of the European Brain Injury Questionnaire and studies into measurement of identity and social processing after brain injury. This work has been driven by the wider context of shifts in measurement science of outcomes as inspired by many of our colleagues.
2. To continue to develop new therapeutic interventions. For example, our latest funded research includes studies of the application of goal management techniques to enable patients to overcome attention and executive difficulties.
3. To continue building procedures for evaluating the impact of rehabilitation through rigorous single case experimental designs and planned international multi-centre collaborations.

We cordially invite interested colleagues to keep in touch with us and collaborate in this endeavour of providing evidence-based rehabilitation for people seeking to overcome the many challenges resulting from brain injury.

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